

HAMPSHIRE COUNTY COUNCIL

Report

Committee:	Hampshire Health and Wellbeing Board
Date:	7 October 2021
Title:	Dying Well: Theme Deep Dive
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1. Purpose of this Report

The purpose of this report is to update the Health and Wellbeing Board on progress by HLOW and Frimley ICS' in relation to End of Life Care key priorities for improvement, outlined below:

- **Priority 1:** Ensure person-centred care, choice and control is consistently in place across Hampshire to help people live well with life-limiting conditions.
- **Priority 2:** Support people at end of life to return to or remain in their preferred setting in the last days and hours of life.
- **Priority 3:** 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.
- **Priority 4:** 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.

Priority 5: 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.

2. Recommendations

The Hampshire Health and Wellbeing Board are asked to support the following recommendations:

1. To agree the current approach and ongoing development of ICS wide End of Life Care Board/Steering Group, enabling end of life care specialists to come together across the patch to drive, develop and enhance end of life care locally. To enable appropriate representation from health, social care and voluntary organisations.
2. To support the developing partnership between Frimley ICS and HIOW ICS as we work together to share learning in the development of end of life care locally.
3. To acknowledge and agree the ICS priorities and deliverables we have identified to date around end of life care, noting that the deliverables will be subject to regular review.
4. To agree the outlined approach specifically related to the following workstreams:

- **End of Life Interoperability**

To support the multiple approaches taken across ICS to tackle interoperability, noting due to the complexity of the challenge that successful and effective engagement and delivery requires sufficient planning and development.

- **End of Life Care Dashboard**

To support plans to engage with the South East Regional work underway to review and develop an end of life care dashboard. Noting that whilst this will result in delays in visibility of ICS wide data, a regional approach will ensure consistency and support to tackle complex issues.

To support discussions with commissioning bodies to outline expectations, supporting by Public Health data expertise.

3. Executive Summary

This report seeks to provide an update regarding the progress of both Hampshire and Isle of Wight ICS (HIOW) End of Life Care Board and Frimley Health and Care ICS Steering Group, regarding the following:

- Priority Workstreams in place
- Achievements to Date

- Plans and Next Steps

The key priorities for End-of-Life Care across each ICS are outlined below, having been determined by the relevant ICS Board/Steering Groups perspective of areas which need further development and aligned with the national priorities. These priorities will be reviewed on a regular basis, informed by the regular update of the End of Life Care matrix – the findings and recommendations from which will be pulled into the ICS work plans and updated accordingly.

3.1 BACKGROUND INFORMATION

HIOW ICS End of life Care Board

Hampshire and Isle of Wight (HIOW) ICS worked closely with lead clinicians across the patch to establish and develop an ICS wide Board focussed on end of life and palliative care around 12-18 months ago.

The Board was established shortly before the pandemic in March 2020 from where work continued to focus on establishing the structure, purpose and ensuring engagement from all key stakeholders.

The Board established their purpose as follows:

1. **Strategy**
To work with stakeholders to ensure we capture and maintain our status of care delivery across HIOW ICS in line with the National Ambitions framework and commit to ensuring this remains current and appropriate to inform our HIOW ICS Strategy and approach.
2. **Clinical Communication**
To work with stakeholders to consider and establish the required set of clinical information to support patients who might be within the last year or so of life, operating within an appropriate Digital solution to enable the delivery of clear, consistent, shared and fully accessible clinical communication across the Hampshire and IOW ICS locality. Findings of an initial pilot to then inform recommendations for a model to be adopted across the HIOW ICS locality alongside a shared standard operating procedure (SOP), Business Change model and shared communication principles which outlines the standard information set and methods of capture to be adopted system wide.
3. **Patient Communication**
Using a public health approach, strengthen the quality of information available to patients and their relatives/carers when considering and receiving end of life care. To make recommendations where needed for the use of information at different stages from diagnosis of LTC/life-shortening condition to final hours and bereavement which promotes consistency of communication and enables informed choice at all times.
4. **Training and Education**
To make recommendations for the delivery of a training and education programme, for all staff involved in the delivery of end of life care. To

enable all staff to be fully equipped to enable conversations with patients and their relatives/carers to happen at the right time and in the right way.

Recognising the complexity of the health and social care system, the Board worked to identify their role within the wider health and social care economy – captured in the network map below. We are extremely proud of the commitment our colleagues have shown across HIOW to support ongoing development of the HIOW EOLC Board, promoting and enabling collaboration across the ICS locality around end of life care, developing and strengthening processes for true co-production with our patients and their families and ensuring both the patient and clinical voice is at the centre of everything we do.

Frimley Health and Care ICS

There are 3 joint chairs for the EOLC steering group. The aim is to support health, social care and voluntary organisations to work together and collaborate on improving services across the system. Children's EOLC steering group feed into the adult steering group. Great working partnerships have been forged with other ICSs.

Some of the desired outcomes identified by the group includes the following:

- People are proactively identified by all health & social care professionals when the end of their lives are nearing, enabling timely conversations on future care planning
- People's wishes around death and dying, including preferred place of care are listened to, respected and recorded appropriately
- People receive high quality palliative care and supportive care, twenty-four hours per day, seven days per week
- End of Life Care providers offer a seamless, streamlined, high quality and holistic service, resulting in people being treated with dignity, compassion and respect at the end of their lives and creating a positive experience of the care they receive
- Carers, friends and family members are supported with preparing for loss and bereavement, continuing after the person they care for has died
- Staff are confident, compassionate and competent to deliver person-centred care and advice which enables a good death
- Care is well coordinated and integrated across multi-disciplinary teams working with and around the person, their carers and families

3.2 Workstreams & Achievements to Date

Hampshire and Isle of Wight ICS

On behalf of HIOW ICS, the End of Life Care Board has worked collaboratively to outline five key principles for the delivery of End of Life Care across the HIOW locality.

These principles recognise there are established EOL networks within each locality, working to deliver programmes of work tailored specifically to the needs of their patients locally. As such, our five key principles act to complement locally driven priorities, reflecting a shared set of deliverables which work to achieve the following on behalf of the HIOW STP:

- 1) To drive, inform and shape the overarching EOL agenda
- 2) To strengthen shared learning associated with EOL care.

A series of working groups have been established to develop the key deliverables outlined below, at an operational level. The working groups have strong clinical, commissioning and provider representation to inform this work.

<p style="text-align: center;"><u>Deliverable 1:</u> <u>EOL Care continues to be a priority, remaining at the forefront of all organisations across HIOW STP</u></p> <p>ALL organisations across HIOW STP will have outlined a clear vision and strategy for End of Life Care, with an established End of Life Network in place to ensure shared discussion, communication and learning across organisational boundaries.</p> <ul style="list-style-type: none"> • To identify a shared overarching vision for the delivery of End of Life Care • To share this overarching vision with all organisations to support the development of EOL strategy where needed 	<p style="text-align: center;"><u>Deliverable 2:</u> <u>Each Person is seen as an Individual & Care is Seamless, Planned and Co-ordinated</u></p> <p>The EOL Board will develop a proposed methodology to capture an agreed dataset within Treatment Escalation Planning and Advance Care Planning across HIOW, to enable:</p> <ul style="list-style-type: none"> • the accurate capture of a patient's individual needs in relation to end of life care • accessibility for all across HIOW via a recognised format/platform • the sharing of information (to amend and view) across HIOW STP locality
<p style="text-align: center;"><u>Deliverable 3:</u> <u>All staff have access to appropriate training resources to support the delivery of quality care</u></p> <p>To identify and bring together the wealth of education and training resources available across the HIOW locality and beyond, to enable the formation of a centralised resource for the provision of high quality training and education material, from which all EOL Care Professionals across health and social care settings can access and benefit.</p> <ul style="list-style-type: none"> • Identify the Stakeholders to be contacted to inform initial understanding of workforce needs. • Understand examples of what works well within the training/education provision across HIOW • Bring group together and co-ordinate development of shared training/education materials. • To create a central resource of appropriate training resources e.g. e-learning, videos etc. accessible to all across the HIOW STP locality 	<p style="text-align: center;"><u>Deliverable 4:</u> <u>Support the early Identification of Patients and Carers</u></p> <p>To strengthen the guidance and processes available to professionals, patients and carers to support an open and competent approach to discussions around EOL, ensuring patients and carers have access to the support needed.</p> <ul style="list-style-type: none"> • To create a "resource pack" of information to provide guidance, structure and tools to support initiating discussions around EOL.
<p style="text-align: center;"><u>Deliverable 5:</u> <u>Bereavement and Care after Death</u></p> <p>Working alongside the Voluntary Sector, the End of Life Care Board will identify examples of best practice and outline opportunities for strengthening the provision of Bereavement and Spiritual Care offered to carers and families across HIOW STP locality.</p>	

Overview of Progress within HIOW ICS End of Life Care Board Workstreams

Deliverable	Progress	Next Steps
Deliverable 1: EOL Strategy	<ul style="list-style-type: none"> EOL Matrix developed and shared by National Team HIOW System populating in line with revised EOL Ambitions 	<ul style="list-style-type: none"> To identify gaps in service To identify challenges in EOL Care To inform strategic approach to then address these gaps/challenges To develop process for regular review of EOL Matrix
Deliverable 2: EOL Interoperability	<ul style="list-style-type: none"> Survey of key Providers expectations sought and analysis shared Initial Agreement in Principle for delivery of Interoperability model drafted Funding for Business Analyst secured and outline of role out for Expression of Interest 	<ul style="list-style-type: none"> Business Analyst to work with Stakeholders to refine Agreement in Principle and Proposed models for delivery Initial model for TEP/ACP underway To develop road map for pilot delivery Links established with CHIE and ICS Technology Board to secure/maintain support
Deliverable 3: Training & Education	<ul style="list-style-type: none"> Mapping exercise of existing training and education provision now complete. Group working to review gaps in provision Links established with HEE to consider adapting learning pathways 	<ul style="list-style-type: none"> Ongoing review of gaps in provision Ongoing development of Learning Pathways

Frimley ICS

This report seeks to provide an update of Frimley Health and Care ICS steering group and priority workstreams that are currently in place as well as the achievements to date.

The key priorities for End-of-Life Care across the FH&C ICS over the next 5 years, outlined below, have been determined by the FH&C ICS End of Life Care Steering Group as areas which need further development, and also align with the national priorities. These priorities will be reviewed on an annual basis and the work plan will be updated accordingly.

Since the start of the strategy the following priorities have been completed:

- The set-up of the End of Life Steering Group, since the COVID-19 Pandemic, this group has continued to meet virtually and work has continued on the task & finish groups
- Completion of the National Framework Ambitions Self-Assessment Tool, this has now been completed twice with more stakeholders completing the self-assessment which is leading to an upward trend in outcomes against the ambitions
- The Production and implementation of a patient diary was superseded by the implementation of ReSPECT across the Frimley system
- Review of the Frimley North Model of 24/7 access to Specialist Symptom Control and Advice, this again was overtaken by COVID-19 Pandemic and formed part of the EoLC COVID-19 Response Teamwork
- Directory of Services was completed and is reviewed on a regular basis to ensure it remains current
- Training & Education Strategy produced and implemented, with ongoing workforce development
- Integrating Children & Young People's End of Life Care, with an EoLC Children's Group set up that feed into the EoLC Steering Group

Due to COVID-19 Pandemic a EoLC response group was set up. The CCGs End of Life Care Team, comprising of the clinical and managerial leads worked closely with the Medicines Management Team to ensure our EoLC Covid Response anticipated the needs of frontline staff and our population. During a very short space of time the team implemented guidance, protocols and pathways to support changes across the system during the pandemic see references below for the Response Team timeline.

Priorities	Work Streams
Education & Workforce	ReSPECT Project Implementation
Health Inequalities	Patient & Carer co-design and engagement with different faith & Cultural Groups e.g. People who are Homeless, Gypsy Roma Traveller (GRT), Learning Disability (LD) and Dementia Improving conversations around dying well and a good death across the Frimley system (Death Fair)

Data & Monitoring	Digital Solutions for Advance Care Plans, aligning with connected Care Reviewing performance and variation
Clinical Effectiveness	Ongoing Best Practice for End of Life Care with supporting business cases for NHSE Funding

HLOW and Frimley have created a close link that is vital for sharing information and lessons learnt on various work areas. Over the last few months, we have joined one another's steering group meetings as part of this shared learning which has provided extremely valuable.

Overview of progress within Frimley Health and care ICS Workstreams

Deliverable	Progress	Next Steps
Deliverable 1: EOL Strategy	<ul style="list-style-type: none"> EOLC self-assessment tool kit used to measure Frimley ICS progress against the 6 ambitions. This has now been completed twice with more stakeholders completing the self-assessment which is leading to an upward trend in outcomes against the ambitions 	<ul style="list-style-type: none"> Gaps identified – now being considered for task and finish groups / tagged onto the current ones. Looking at ways to continue improving in those areas that we are progressing well.
Deliverable 2: ReSPECT implementation	<ul style="list-style-type: none"> Project Manager is in post, leading on RESPECT work. Training is being offered across Frimley ICS 	<ul style="list-style-type: none"> ReSPECT to be BAU by end of October Training data to be maintained and reviewed regularly to identify where support is needed. Data from ReSPECT to be used for EOLC data dashboard
Deliverable 3: Training & Education	<ul style="list-style-type: none"> Mapping of EOLC training completed. Localised version of levels of training was produced for all organisations across the ICS. 	<ul style="list-style-type: none"> Ongoing review of training and education by the steering group
Deliverable 4 Multicultural and EoLC	<ul style="list-style-type: none"> ReSPECT to be BAU by end of October Training data to be maintained and reviewed regularly to identify where support is needed. 	<ul style="list-style-type: none"> Staff booklet is ready for publishing and circulation.

	<ul style="list-style-type: none"> • Data from ReSPECT to be used for EOLC data dashboard 	<ul style="list-style-type: none"> • Videos (films) to be created that focus on encouraging the public from different backgrounds to access EOLC.
Deliverable 5 Bereavement and Care after death	<ul style="list-style-type: none"> • 5 Death Fair sessions were delivered over a period of 5 months. • Positive engagement with the general public and other areas that need addressing were raised. This has informed future topics to be covered in the future • Bereavement leaflets published 	<ul style="list-style-type: none"> • Plan activities every year during Dying Matters week • Future topics to be based on feedback from previous Death Fair sessions. • Consider sessions that encourage under represented communities to join e.g. man only Death Fair sessions

4. Partnership working

The South East Region have pulled together a Palliative and End of Life Care Leads Group during 2021/22, where leads from across the South East attend to discuss end of life care. This has enabled shared discussions across the South East to identify the following priorities related to PEOLC:

1. Hospice Provision

Escalation of concerns related to the Hospice provision and the impact of Covid, resulting in reduced charitable income has led to additional funding secured for Hospices during 2020/21. Following this, a series of workshops are underway to develop our understanding of the new Hospice commissioning framework co-ordinated by the central team and utilising their expertise to inform discussions.

2. End of Life Care Dashboard Development

Recognising the value of oversight of End of Life data across the ICS and indeed the South East, the Regional team have formed a working group to develop a consistent approach across the South East and provide specialist expertise to these discussions. The aim of the group is to create an online dashboard that can be accessed by all ICSs in the SE region. Each ICS will be able to filter data to local level and identify areas that need addressing or gaps in care. This initiative is in its infancy and currently gathering data profiles from all ICSs.

3. Out of Hours Care for End of Life

Identified as a priority. Further details have yet to be developed.

4.1 Local Partnership Working

Strong links have been developed between Frimley and HIOW ICS End of Life Care Groups which active sharing of expertise and learning. HIOW have particularly valued the shared learning received from recently held Death Fairs to inform the development of similar sessions within HIOW, including a pilot within Portsmouth seeking to engage with the BAME community.

Strategic links have been established between adults and children's end of life care, with learning being shared to inform the development of a Childrens EOLC Clinical Network.

In response to the development of an ICS EOLC Board in each area, the Hospices have come together to establish a HIOW Hospice Collaborative which works closely with the Boards in the development of EOLC locally. Work is now underway to develop a Frimley Hospice Collaborative linking in with Frimley ICS.

4.2 Coproduction: User & Community Engagement

Across both ICS', patient representation has been sought to support various workstreams. Alongside this, the working groups seek wider additional feedback from existing patient forums as and when required.

However, we recognise that further efforts need to be taken to strengthen and enhance how we engage with our community around the development of end of life care. Recognising this, each ICS has taken action as follows. The learning from both these approaches will be shared as part of the regular partnership working arrangement.

- **HIOW ICS:** Building on Alongside Communities Approach - A community conversation with patients, families, carers and those who support them scheduled 1 October 2021 to guide our next steps
- **Frimley ICS:** Multicultural videos – patient experiences to be captured via films. Patients will be from different ethnic backgrounds.

5. Challenges

Our Challenges we have experienced are detailed below, these inform the support we now request from the Health and Wellbeing Board:

- a. **Access & Oversight of ICS wide data:** Identified as a priority workstream by SE Regional EOLC Team. Frimley and HIOW are both engaged in the working group to inform the development of a South East wide dashboard and improved access and visibility to key measures associated with end of life care.

We request that the Hampshire Health and Wellbeing Board support plans to engage with the South East Regional work underway to review and develop an end of life care dashboard. To do so by supporting discussions with commissioning bodies to outline expectations (supported by Public Health expertise). In the event of any arising blockers it would be helpful to have the backing of the Board in facilitating and challenging the carriers. Whilst this will result in delays in visibility of ICS wide data, a regional approach will ensure consistency and support to tackle complex issues.

- b. **Resources and Expertise:** Initially the impact of Covid-19 had resulted in pausing some of the groups. Hence, timelines affected. Now all groups have restarted. Added to this, there have been some challenges with capacity and resources within end of life care services which has led to some workstreams to be put on hold/delayed.

The Board could intervene by availing additional funding to minimise the number of workstreams that may potentially be put back because of limited capacity.

- c. **Workforce Resource and Expertise:** Challenges around stability of workforce and maintaining consistency of end of life expertise, due to recruitment and retention alongside complex training required.

A specific issue identified by Frimley related to capacity for specialists to support development and delivery of key workstreams: Previously Homelessness and EoLC workstream had to be paused. One of the clinical lead's funded post ended and there was no alternative funding in place.

Health and Wellbeing Board to be aware of these challenges faced and continued work to address this within service and across ICS'.

- d. **Engagement of some key stakeholders (Users/Primary Care/ASC) has proved challenging:**

Request support from the Health and Wellbeing Board to improve engagement with our partners by identifying potential opportunities for engagement and supporting leads identified to prioritise this work. For the board to offer advice of how we could approach these challenges and seek to address.

Within HIOW, this relates to Primary Care, User representation and Adult Social Care. Within Frimley, this relates to Adult Social Care representation.

- e. **Complexity of digital interoperability agenda to enable user access:** Agreement to our approach to pilot small scale services within patch (HIOW) and support prioritisation of agenda at technology boards.

- f. **Continue to consult together around Dying Well Agenda:** to work together to review and update the Dying Well plan in line with current requirements, thereby informing a revised business plan for the future delivery of the health and wellbeing, dying well strategy. Alongside this, to clarify the process for ongoing reporting and escalation to ensure any potential challenges are supported where needed.

Despite the challenges faced by both HIOW and Frimley Health and Care ICS work is progressing. The continued collaboration between the ICS' and stakeholders will ensure better management of resources and avoid running concurrent initiatives individually. On completion of SE regional data dashboard task and finish group work, a fully operational data dashboard will enable the ICSs to have data at hand which will paint a clear current state situation and inform future intervention.

REQUIRED CORPORATE AND LEGAL INFORMATION:

Links to the Strategic Plan

Hampshire maintains strong and sustainable economic growth and prosperity:	No
People in Hampshire live safe, healthy and independent lives:	Yes
People in Hampshire enjoy a rich and diverse environment:	No
People in Hampshire enjoy being part of strong, inclusive communities:	Yes

Section 100 D - Local Government Act 1972 - background documents

The following documents discuss facts or matters on which this report, or an important part of it, is based and have been relied upon to a material extent in the preparation of this report. (NB: the list excludes published works and any documents which disclose exempt or confidential information as defined in the Act.)

Document

Location

None

EQUALITIES IMPACT ASSESSMENT:

1. Equality Duty

The County Council has a duty under Section 149 of the Equality Act 2010 ('the Act') to have due regard in the exercise of its functions to the need to:

- Eliminate discrimination, harassment and victimisation and any other conduct prohibited by or under the Act with regard to the protected characteristics as set out in section 4 of the Act (age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation);
- Advance equality of opportunity between persons who share a relevant protected characteristic within section 149(7) of the Act (age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation) and those who do not share it;
- Foster good relations between persons who share a relevant protected characteristic within section 149(7) of the Act (see above) and persons who do not share it.

Due regard in this context involves having due regard in particular to:

- The need to remove or minimise disadvantages suffered by persons sharing a relevant protected characteristic that are connected to that characteristic;
- Take steps to meet the needs of persons sharing a relevant protected characteristic that are different from the needs of persons who do not share it;
- Encourage persons sharing a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.

2. Equalities Impact Assessment:

It is expected that equality impact assessments would be completed as appropriate across the system for specific work programmes or decisions that feature in the business plan.