You Said - We Did Report

August 2023

Coventry and Warwickshire Palliative and End of Life Care Strategy and Delivery Plan 2024-29 Engagement.

Background

This document is an overview of the feedback we have received though the co-production and engagement undertaken to support the development of the Palliative and End of Life Care (PEoLC) strategy, which was undertaken in various stages from June 2022 – July 2023.

The PEoLC Strategy details how health and social care will work together with our communities across Coventry and Warwickshire to improve the lives of people with palliative and end of life care needs and those who look after them.

This strategy is for everyone in Coventry and Warwickshire both for the people who live here and the people who work in health, social and third sector organisations across the system.

We have asked people with palliative and end of life care needs, their carers, those who live in Coventry and Warwickshire, as well as our partners in health and social care, what we should focus on to improve the care and support we provide to people who are nearing the end of their lives. We have listened to many people about what matters most to them when experiencing care themselves or caring for someone important to them.

Through engagement we reached out to:

- Over **1,600** people including patients, the public, health, social and third sector professionals.
- Over **300** organisations across Coventry and Warwickshire

Through co-production and engagement:

- We have directly spoken with representatives from over **30** different community groups and health and social care organisations via face to face or small group meetings.
- We have undertaken a series of public and stakeholder surveys and received a total of **239** responses from across the system.

We would like to take this opportunity to thank everyone who took the time to actively participate in the engagement.

Your feedback has enabled the development of the Coventry and Warwickshire Palliative and End of Life Care Strategy and has helped to ensure the 2-year Delivery Plan focuses on the right priorities which will have the greatest impact on improving care for people in Coventry & Warwickshire who are approaching the end of their lives.

We will continue our engagement and co-production ethos throughout the life of the strategy to ensure we are working with people, communities and professionals to develop effective and efficient end of life care for all our diverse communities.

We have developed 5 priorities based on feedback we have received through the development process of this Strategy.

Our Priorities: What we want to do.
1. Provide **information** which focuses on identification, early intervention, and support for people with palliative and end of life care needs.
2. **Access** to timely palliative and end of life care with support throughout, for all of our diverse communities.
3. **Support** people diagnosed with a life limiting condition and those who matter to them, carers and communities.
4. **Improve** the quality of personalised care and support planning for people with palliative care needs, including planning for the end of life, through education and training for all.
5. Deliver a **sustainable** system of integrated palliative and end of life care

General Feedback Received

The engagement has provided us with a wealth of information to help shape the final strategy.

In general, the responses have been positive, including the following statements:

"It was an easy read and pleased to see consideration to those with protected characteristics and groups with largest gap of inequalities"

"I am happy that the delivery plan provides a robust high-level approach"

"It looks a good piece of work"

"I thought infographics are good"

"I feel all the points and priorities are covered"

"Overall, I think this is a great piece of work with an easily accessible format"

"I think this is a very well written and considered document, summarising all the stakeholders work and input"

"The strategy document itself is straightforward and well written. I would agree with all priorities"

"I thought there were a number of positives about the strategy – including that there was a detailed delivery plan linked to it, it had a clear focus on health inequalities, and it used easily memorable priorities"

We have collated the received feedback in the table below, which we have grouped thematically and utilised in several ways to further develop and finalise the Palliative and End of Life Care Strategy.

We have detailed how we have utilised this specific feedback to develop a robust delivery plan with clear actions and outcomes to improve palliative and end of life care.

Priority	You Said	We Did

Priority 1: Information	• Tools for identification need to be agreed for the system as a priority
	• Patient information leaflet should be developed and promoted
	• Need for consistent documentation for Advance Care Planning, as well as a consistent approach on recording and sharing
	• Need for public education around death and dying
	• Explore an approach to a joined-up system Single Point of Access
	• Better understanding needed of terminology used e.g., distinction between Specialist Palliative Care and End of Life Management with associated palliative support
		• Systemwide agreement for development of a PEoLC identification pathway is in the delivery plan
		• Systemwide agreement for development of PEoLC service directory and service information for the public, health and social care professionals
		• Systemwide agreement for review of current advanced care planning documentation and electronic methods of information sharing.
		• Plan a systemwide approach for Dying Matters week 2024
		• Continue to work in collaboration with the Out of Hospital review
		• Continue to work in collaboration with the CASTLE Expert Advisory Group
		• Agreed Task & Finish groups to be established:
		  • Identification Pathways
		  • Advance Care Planning
		  • Review of iPlan
		  • Website Design

Priority 2: Access	• Awareness of workforce gaps e.g., Clinical Psychology provision
	• Overuse of UCR (Urgent Community Response) & rapid response
	• 24/7 access to medications:
	  • Difficult to access in communities
	  • Needs patient voice
	• Challenges in accessing:
	  • 24-hour hospice care
	  • Equipment for patients to die in their home
		• Systemwide mapping of workforce underway
		• Systemwide mapping of current services underway
		• Review of utilisation of urgent and emergency care services by patients in the last 3 months of life commenced.
		• Access to medications workstream set up with systemwide representation
		• Data workstream to look at cross boarder sharing
		• Proactive and unplanned care to be incorporated into the delivery plan
		• Continue to work in collaboration with the Out of Hospital

Priority	You Said	We Did
	• Data across counties e.g., a child under Birmingham Childrens hospital & Warwickshire • Hospices for children over 5 • After-death clinical provision for deaths in A&E	review

Priority 3: Support	• Lack of availability of information around the existing support options for end-of-life care
	• Lack of collaborative working between different specialities
	• Patients not prepared or supported for shared decision-making conversations
	• Support needs identified:
	  • Siblings and identification of siblings in need of support
	  • Face to face support for patients to enable encourage to access services
	  • Bereavement needs for those who have lost a child or young person
	  • Needs patient voice
	  • Formal acknowledgment for the role of the carer
	• Training needs identified
	  • Palliative and end of life care in care homes
		• Systemwide agreement for development of PEoLC service directory and service information for the public, health and social care professionals
		• Mapping of different programmes aligned to PEoLC, e.g., dementia, long term conditions, frailty, learning disabilities, virtual wards etc included in the delivery plan.
		• Education and training Framework for the system to be developed as part of the delivery plan to support staff, patients and those important to them, including scoping of currently available training.
		• Explore support available specifically for siblings and ways to measure sibling experience
		• Loss of a child or young person will be included in our bereavement scoping work
		• Promotion of social prescribing

Priority 4: Improve	• Competency framework for the system including training directory for all levels, training/education passport • Teaching healthcare professionals and the public on the recognition of dying • Sharing good practice about what makes a good PCSP	• Development of a PEoLC Competency Framework part of the delivery plan • Work with CASTLE Education group and other PEoLC Education leads across the system to develop plans • Systemwide approach for dying matters week • Education and training scoping underway and to include

Priority	You Said	We Did
	(Personalised Care and Support Planning) and how to achieve this • Requirements for specialist and generalist end of life care • Ensuring access to training for anyone who needs it e.g., standalone care providers • Awareness of the diversity of the community we serve	standalone care providers • EQIA (Equality and Quality Impact Assessment) undertaken • Continued engagement with our population of Coventry & Warwickshire, including hard to reach communities
Priority 5: Sustainability	• Need a better understanding of current roles and gaps in services • Workforce Planning should align with the national workforce plan for the next 15 years	• Systemwide workforce mapping underway • Recognition of national workforce plans to be incorporated as part of the delivery plan.
Language & Layout	• Abbreviations need clarification & clearer infographics needed • Terminology used	• All abbreviations reviewed and a glossary added • Improved infographics to be sourced during design phase of strategy • Terminology used has been sourced to ensure consistency with language use nationally in the public forum.
Promote Collaborative working across the System	• Need to develop relationships and increase the ways of working together • Delivery of the strategy relies on integration and communication between all services	• Collaborative working has been at the heart of our strategy draft and engagement and will continue to be promoted in the action and delivery plan, as well as any workstreams created
Other	• Has an Equality Quality Impact Assessment been completed • How might you measure 'what does good look like' in terms of patient experience. • Mental health issues including dementia should be added to the list of health inequalities • Looked after Children and Adopted should be added	• EQIA has been completed • To explore patient experience feedback across the system • Both added to health inequalities list

Priority	You Said	We Did
	to the list of health inequalities • How are we tackling access and financing information & resources for non-English speaking and reading population? • Understanding the holistic needs of the population	• This has been explored in our EQIA and we will continue to engage with these communities to identify the support they require • Personalised care is the golden thread throughout the strategy