

Paper Title	System Review of End of Life Care and Experience Review Methodology , Scope and Governance (Terms of Reference)
Paper Details	<p>Paper for : Joint Health and Overview Scrutiny Committee (JHOSC)</p> <p>Date : 22/10/2020</p> <p>Author : Tracey Jones Deputy Director Integrated Care NHS Telford Clinical Commissioning Group</p> <p>Presenter : Alison Massey Senior Project Manager End of Life Review</p> <p>Purpose : Update JHOSC on End of Life System Review</p>
1.Background to Review	<p>1.1 This review was initiated in response to consideration of public feedback both at NHS Shropshire Clinical Commissioning Group (CCG) and Shropshire Community NHS Trust Boards with respect to:</p> <ul style="list-style-type: none"> ▶ End Of Life (EOL) planning and provision in Shropshire, Telford and Wrekin ▶ Freedom of Information questions about out of hours primary care provision to enable EOL Care <p>1.2 Additionally both Shropshire and Telford &Wrekin Clinical Commissioning Groups have considered feedback shared by Telford and Shropshire Healthwatches following Surveys relating to Experiences of End of Life and Palliative Care (Healthwatch Telford & Wrekin : Dec 2019) (Healthwatch Shropshire : Jan 2020). There is a current live Out of Hours Palliative Care Survey hosted by Healthwatch Shropshire on its own and Telford &Wrekin Healthwatch behalf. This can be found at https://www.healthwatchshropshire.co.uk/out-hours-palliative-care-survey</p> <p>1.3 The approach and methodology for the review reflects discussions held with Joint Health and Overview Scrutiny Committee (JHOSC) in August 2020.</p> <p>1.4 This review was proposed and accepted as a system priority project for the Sustainability and Transformation Partnership in September 2020 and was assigned a lead Senior Clinical Commissioning Officer to take it forward.</p> <p>1.5 The proposed review methodology and terms of reference (aim, scope, expected outputs, timing and governance) has been shared with the following stakeholders/ groups and comments incorporated.</p> <ul style="list-style-type: none"> ▶ Telford & Wrekin Healthwatch ▶ Shropshire Healthwatch ▶ Local End of Life Specialist Clinicians ▶ Shropshire Partners in Care ▶ Clinical Commissioning Group Executive Lead ▶ Sustainability and Transformation Partnership Clinical lead ▶ System Health and Social Care senior leaders via the Community and Place Based Programme Board ▶ Primary Care Network Development Meeting

<p>2. Review Aim <i>What we hope to achieve</i></p>	<p>The purpose of the review is not to develop a strategy but to review how we can make impactful change on individual's experiences by learning from feedback and working together as a system</p>
<p>3. Review Methodology <i>How we shall approach achieving the aim</i></p>	<p>3.1 A service review traditionally is led by an agenda set by Commissioners. It normally includes commissioners undertaking data collection, performance reviews, regional and national benchmarking exercises and considering achievement against set criteria for providers of the service under review.</p> <p>3.2 This usually includes conducting surveys and gaining the perspectives of individuals and their families and other stakeholders. The expected outcome is normally a report with a set of recommendations or actions.</p> <p>3.3 However this system review does not wish to follow the traditional approach as that focuses more on individual providers and those receiving care will often do so from multiple providers. The alternative approach seeks to foster the co-development of solutions across the whole of the pathway.</p> <p>3.4 As a system we have already come together to develop aspirations of cross system working through the development of a plan on a page for End of Life Care (see Appendix One). This review seeks to build on that system working.</p> <p>3.5 The methodology for the review is based on using the information we have in our system already which tells us about how elements of end of life care are experienced across pathway/ providers by the individual and their families as well as the staff and managers involved in delivering these services. (See stakeholder list in section 8).</p> <p>3.6 The review will have two phases</p> <p>3.6.1 Phase 1 The review will request stakeholders to reflect themselves on the feedback they have had from people receiving services and their families, the public, their staff and any sources of data such as performance monitoring, CQC feedback, strategy reviews.</p> <p>They will be requested to submit up to 4 questions that are phrased in positive improvement terminology based on this reflection. E.g</p> <ul style="list-style-type: none"> ▶ How can we improve ...? ▶ How could we change experience in relation to ▶ How do we ensure that <p>The areas they select to be put forward for inclusion do not have to relate just to their own organisation and it is expected that the areas put forward will cross over providers.</p> <p>Healthwatch Shropshire and Healthwatch Telford&Wrekin will be included as an equal partner and requested to put forward questions from the perspective of public and individual feedback.</p> <p>Through its complaint processes Clinical Commissioning Groups actively request if individuals are prepared to contribute to service developments concerning the nature of their complaints. It has been identified that there are individuals who are willing to be interviewed in relation to End of Life Care experiences. Interviews will be conducted on an individual basis by the Senior CCG Officer responsible for the project who is an experienced clinician in End of Life Care and patient</p>

	<p>engagement. This listening to individual stories will continue throughout the life cycle of the review and information fed into appropriate workstreams (see Phase 2 below).</p> <p>Following completion of this first phase of the review, a collective workshop will be arranged which will allow for the selection of the 4 key themes/ questions. Due to Covid social distancing restrictions this will be held virtually and consideration to enabling full participation will be given.</p> <p>3.6.2 Phase 2 Task and finish groups will be established to address the questions selected using an action orientated approach.</p> <p>The leads and membership of the groups will be drawn from across the system dependent upon themes/questions selected with a commitment to involve people with lived experience as a core principle.</p> <p>Each individual group will be tasked with</p> <ul style="list-style-type: none"> ▶ Collectively understanding the feedback from stakeholders relating to the question ▶ Considering solutions to the question ▶ Where appropriate using Plan, Do, Study, Act methodology to trial solutions and then use implementation planning to embed changes. ▶ Where necessary escalate solutions requiring formal system agreement and /or additional resources to the Senior Responsible Officer who will raise with the Community and Place Based Board and where necessary Chief Officer Gold Command.
<p>4. Scope of Review</p>	<p>4.1 In defining the scope of the review, the system does not place less importance on the impact / experience of End of Life Care outside of those included in this scope; rather it seeks to provide a focus for change within its timescales.</p> <p>4.2 The review scope (as agreed by system partners shown in section 1) is</p> <ul style="list-style-type: none"> ▶ Limit to Adults 18 upwards ▶ Focus on Expected not sudden End of Life Death expected within the next 12 months. Includes those whose death is imminent (expected within a few hours and days)) ▶ Limit to 4 Key Improvement Questions which will be driven through co-production and not set by the Senior CCG Officer leading the review
<p>5. Expected Outputs</p>	<p>5.1 The expected outputs will be developed as part of the working groups that will be formed to address the questions generated through the process described above in section 3.6.1.</p> <p>5.2 It is expected these will reflect improvements across the following criteria</p> <p>(a) Improved Quality and Experience Outcomes for People : (Reflecting national best practice e.g One Chance to get it Right)</p> <ul style="list-style-type: none"> (i) patient and family/ carer experience (ii) staff experiences and sense of job satisfaction (iii) clinical outcomes and quality of life outcomes (iii) patient safety

	<p>(b) Cost Effectiveness and Financial Sustainability: Shropshire, Telford and Wrekin CCG's are committed to the delivery of Services which are cost effective and financially sustainable.</p> <p>(c) Equity: Workgroups will be specifically asked to consider the impact of health inequalities on their questions and the need to consider the additional rural /urban divides in Shropshire, Telford &Wrekin.</p> <p>(d) Integrated Care Pathways: Providers of services commit to work across organisational boundaries to improve experiences and reduce duplication and therefore contribute to achievement of criteria b above.</p> <p>(e) Impact on other Services: Changes to one area may have unintended consequences on other services, statutory and voluntary, groups will be required to consider this when planning outputs.</p> <p>(f) Clinical Sustainability: It is widely acknowledged that we are challenged in terms of workforce recruitment. Any proposed outputs need to consider that Service provision is clinically sustainable</p> <p>(g) Feasibility: The process of change must be feasible and deliverable.</p>
<p>6. Governance</p>	<p>6.1 Reports on the progress of this review will be required to be provided to the Community and Place Based Programme Board. This is a subgroup of the Transformation Board and System Integrated Care Shadow Board. This will ensure the appropriate degree of senior scrutiny and escalation of issues requiring further system resolution. Reports will also be provided to Joint HOSC for information/ discussion throughout the duration of the review.</p> <p>6.2 The working groups addressing the 4 key questions will report into a steering group which will be formed from expanded membership of the existing End of Life Review Group and utilise time already allocated to this system meeting to reduce duplication. This will be subject to review in relation to size of agenda and issues requiring escalation to the steering group.</p> <p>6.3 Current Membership of this group includes</p> <ul style="list-style-type: none"> ▶ Severn Hospice ▶ Shrewsbury and Telford Hospital Trust ▶ Shropshire Partners in Care ▶ Shropshire Community NHS Trust ▶ Robert Jones and Agnes Hunt Foundation Trust ▶ Shropshire, Telford & Wrekin CCG Quality and Commissioner leads ▶ Shropdoc Out of Hours Provider ▶ Macmillan Lead GP <p>6.4 It is proposed the membership of the board is expanded to include</p> <ul style="list-style-type: none"> ▶ Healthwatch Representation as independent patient voice ▶ Review Lead Senior Responsible Officer ▶ Review Senior Project Lead ▶ Workstream Leads (the expectation is that existing members of the group will be approached to take on this role due to their senior clinical status and pre-existing connection to EOL care, however alternative leads may be selected based on the outcomes of phase 1 such as mental health leads or workforce/training leads)

7. Indicative Timelines	Action	Timelines	Responsible Lead
	Planning 1. Develop methodology	Commence 15 th Sept 2020	Tracey Jones
	2. Gain collective agreement for methodology and Terms of Reference (aim, scope, expected outputs, timing and governance) across a wide range of stakeholders.	8 th October 2020	Tracey Jones
	3. Complete stakeholder mapping / identify key individuals to respond to Phase 1	12 th October 2020	Tracey Jones
	Phase 1 – a) Project lead to contact stakeholders with brief for their reflective review	Week commencing 12 th October	Alison Massey
	b) Stakeholders complete reflection on known information and return questions to Project lead	Return Date 30 th Oct	ALL
	c) Process for collaborative agreement designed	Complete by 26 th Oct	Alison Massey
	d) Collaborative discussion and 4 key questions co-produced/agreed	ALL	12 th November
	Phase 2 – a) Identify workstream leads b) Establish workgroups c) Begin codesign and testing of solutions	TBC and further developed post Phase 1	20 th November onwards
8. Stakeholders	A: Patients/ Carers/ People with lived experience	Self-identified through complaints and PALs Teams	
	B: Public / Communities	Healthwatch Macmillan Representatives	
	C: Communication and Engagement	Via STP Comms and Engagement Lead	
	D: Staff / Organisations -	Primary Care Robert Jones and Agnes Hunt Severn Hospice Shrewsbury &Telford Hospital Shropdoc Shropshire Community NHS Trust Shropshire Local Authority Shropshire Partners in Care Telford Local Authority WMAS	
	E: Planners and Commissioners -	NHS Shropshire CCG NHS Telford CCG	

Appendix One

T&WCCG.SCCG/Councils?

The Shrewsbury and Telford Hospital NHS Trust



Shropshire Community Health NHS Trust



Severn Hospice



Local Health Economy End of Life and Palliative Care Strategy

Caring, Responsive, Effective, Well-Led, Safe: A positive experience for patients, carers and families



National Ambitions

Individual care

Fair access to care

Comfort and Wellbeing

Coordinated care

All staff care

Caring Community



Facilitate effective personalised care planning and support of those important to the dying person

- Documentation provides clarity to all regarding patients' preferences/goals for living
- Important conversations
- Identify key worker
- Patient and carer access to documentation
- Shared electronic records

Ensure equal access to palliative and end of life care

- Develop systems with prognostication to identify patients in last year of life
- Co-ordinated processes for referral: clear Access criteria and Co-designed referral documents
- Establish a needs based model that identifies phase of illness and a system for prioritization
- Links with non-cancer specialists
- All supported by GSF and Frailty registers
- Support Transitional Care Initiatives

Establish 'Living Well' concept: support advance & anticipatory care planning & timely access to services

- Culture of care is enablement
- Programs for palliative rehabilitation are established
- Expand homecare models to support a preference to die at home; further develop H@H service
- Provide necessary medication and associated documented administration authority

Work in partnership to ensure that care is coordinated between services

- Facilitated by Local Health Economy End of Life Group supported by CCGs
- Services compliment not replicate each other
- There is shared accessible documentation where possible (RESPECT, EOL care plan, PPC) and Flagging
- Integration of services and System learning from Significant Adverse Events

Ensure a competent workforce

- Identify education needs across services; Establish education programmes
- Robust systems for appraisal and CPD including verification of death

Recognise compassionate communities voluntary support as an extension to services

- Severn Hospice continued roll out of coco
- Volunteering is seen as an arm to wider services
- Clinical services refer to established volunteer support
- Expand competencies in verification of death to facilitate this promptly and confidently

National Foundations

Personalised care planning

Shared records

Evidence and information

Those important to the dying person

Education and training

24/7 access

Co-design

Leadership



Living Well HELPS ---> Dying Better