



## Summary

How healthy are our palliative care and end of life systems? What are the Vital Signs? This case study shows how the South West End of Life Network has worked to find a way - as simple as possible - to get a rapid sense for how well it's going and to enable improvements:

- At the level of the individual and their family
- At a local level
- Across a whole integrated care system
- As a region.

An example of generative governance in practice, including commissioners, clinicians, managers alongside people with lived experience.

# Vital Signs -End of Life Network, NHS England - South West

## | Overview and history

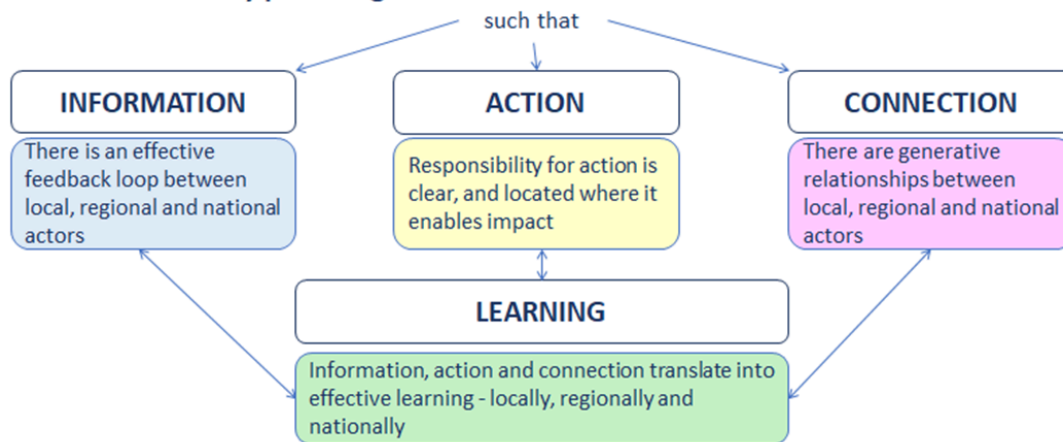
This is a new example of HLS practice.

The South West End of Life Network is a community of people involved in palliative care and the last years of life across the South West. It was established in 2020, hosted by NHS England - South West. A small team enables coordination of the Network - regular opportunities for people to meet and talk about things that matter to them; co-design; support to local and regional learning initiatives. This enables feedback loops - flow of information between local, regional and national teams.

The Vital Signs group - part of the South West End of Life Network - includes clinicians, managers, commissioners and people with personal experience of caring for someone at the end of their life.



Ensure, enable and improve personalised care – especially at end of life  
by providing coordination and communication



Do use the language if ‘Human Learning Systems’ to describe your approach? If not, what other language do you use?

We don’t usually use the term ‘Human Learning Systems’ to describe our approach. The language we use depends on context.

## | HLS Approach

### | Human

Describe what is ‘Human’ about how you work [with reference to the ‘[Human](#)’ chapter’ of “Human Learning systems: public service for the real world”]

- We care about each other as people - seeing the person over their role or their illness, set of conditions or ‘needs’
- We encourage seeing people in their context, recognising what’s happening in the real world.
- We see improvement as social as well as technical, and relational work being at the heart of what we do.

### | Learning

Describe how you have enacted Learning as a management strategy [with reference to the ‘[Learning](#)’ chapter’ of “Human Learning Systems: public service for the real world” or the [Practical Guide for the Curious](#)]

We favour rapid, iterative small-scale tests of change over implementing “programmes”.  
We make time for regular check-ins to develop, learn from and iterate tests of change.

We undertake synthesis of learning locally and regionally:

- to make visible the patterns we are seeing
- to validate with local, regional and national actors - iterating accordingly



- to articulate possible future actions and
- to co-design next actions.

## | Systems

**What is the ‘system’ that you have worked with/brought together? (i.e. who are the people/organisations involved? What work have you done to help them learn together?) [with reference to the ‘[Systems](#)’ chapter of “Human Learning Systems: public service for the real world”]**

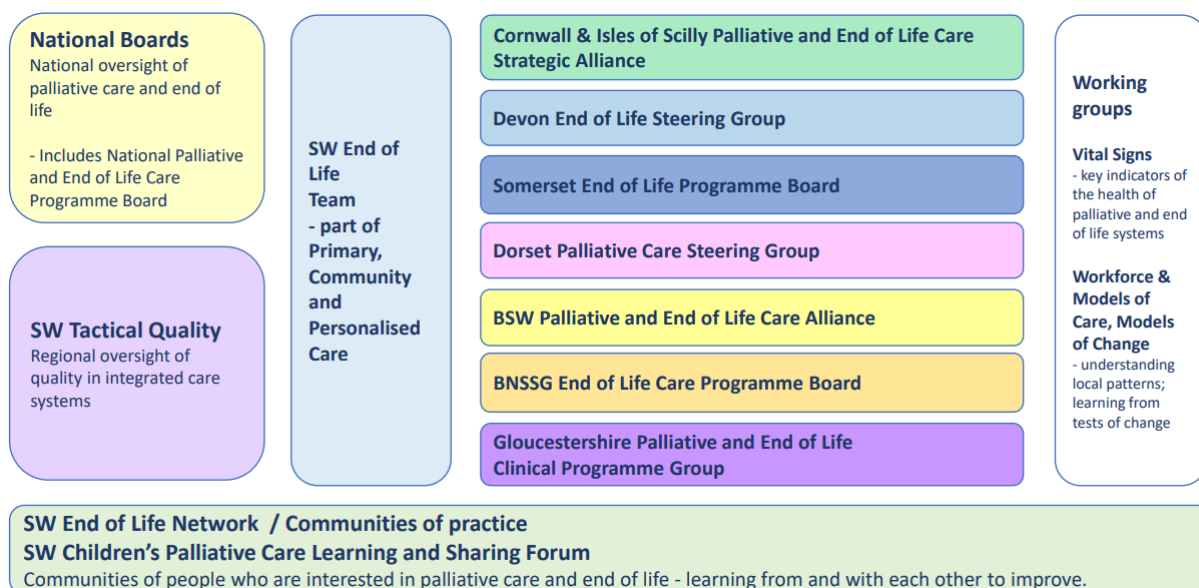
The Network brings people together from a range of perspectives in relation to palliative care and last years of life - including people working in health and care systems (as clinicians, managers, commissioners) and people with lived experience of caring for someone close to them towards the end of their life.

Colleagues work in a wide range of organisations - NHS (GP practices, acute hospitals, community trusts, hospices, commissioners, regional teams), voluntary and charitable organisations, independent hospices, hospice@home, community groups, carers groups, care homes.

## | Governance/Accountability

**How is this work being governed? How have your governance or accountability processes changed to work in a Human Learning Systems way?**

Each integrated care system (ICS) is responsible for commissioning palliative care, as set out in the Health and Care Act 2022. Each ICS in the South West has a Group, Board or Alliance focusing on Palliative and End of Life Care. This work has brought together people from ICSs across the South West to identify and test key measures of the health of palliative and end of life care systems. The work is coordinated by the South West End of Life team, enabling visibility at regional and national levels.



## | Story of Change



In 2022 the South West End of Life Network initiated four collaborative Learning Enquiries to delve deeper into these questions, co-designed by the Network:

- What data/insight can help us track improvements in our capability to do what matters?
- What are the predictable 'personas' or 'scenarios' where the system struggles or fails? Why?
- What are the pros and cons of different models of care - and what are the key ingredients?
- How can we sustainably commission joined up services that benefit people in our local communities?

Building on these learning enquiries, a working group embarked on collaborative work to identify 'Vital Signs' for palliative care and end-of-life. The intention was to enable a rapid sense of the health of palliative care and end-of-life systems across the South West - "taking the pulse" rather than "mapping the genome".

The Vital Signs group identified over 150 measures that people were looking at across the region, but there was no single definitive approach. They honed the measures down to nine key themes and then simplified further to three key areas:

(1) How well do we identify people who are approaching the end of their life?

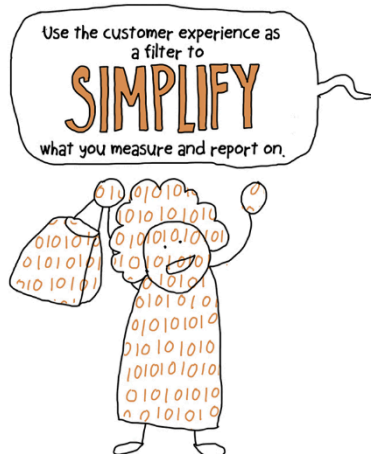
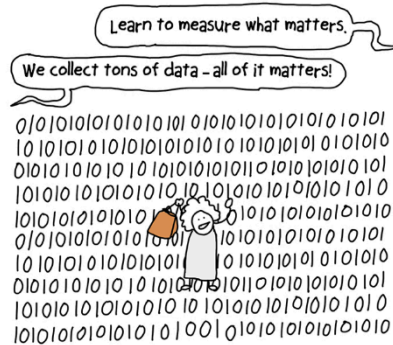
(2) What's people's experience? How is it going? Looking back, how did it go?

(3) What healthcare activity takes place in the last 90 days of life? (for example, outpatient attendances, 999 calls, attendances at Emergency Departments, emergency admissions to hospital). Where do people die?

The Vital Signs group is focusing on (2): developing and iterating simple approaches to understanding experience - how's it going and how did it go?

We have been working with Medical Examiners and Medical Examiners' Officers to gather insights from bereaved families.

We worked with Business Intelligence teams / data analytics on (1) and (3).



Cartoon by Virpi Oinonen - [virpi@businessillustrator.com](mailto:virpi@businessillustrator.com)

## | Barriers and Tensions

**What difficulties did you encounter? How did you respond to them?**

### *Priorities and preferences*

Local priorities, local preferences, habits and history (e.g. which measures people were accustomed to using) meant that it took some time to agree on key measures.

We responded by:

- Recognising and welcoming divergence, recognising that there isn't one "right answer".
- Using a design approach - welcoming all (>150) ideas before narrowing down together.
- Being explicit about benefits of adopting a consistent approach across the region.

### *Approaches to change*

A "business-as-usual" approach would be to design, pilot, and implement. Using an iterative approach through Tests of Change isn't familiar to everyone and is still relatively counter-cultural.

We worked through this by:



- Regular frequent check-ins (meeting weekly initially, then fortnightly), focus on learning.
- Favouring testing something which is “good enough” rather than spending weeks or months trying to design something to perfection.
- Focusing on rapid learning loops, grounded in practice, and being action-oriented.

## | Enablers

### What were the factors/conditions which enabled you to adopt an HLS approach?

#### *Stewardship and support:*

- Regional end of life team, support of the regional senior responsible officer and leads within integrated care systems.
- Vital Signs is one of a small number of priorities for the regional end of life team in 2023/24 - by limiting work in progress, we have been able to make significant progress with this.
- Embracing the importance of learning from patient and family experience in local organisations (for example, NHS trusts) has helped to create an enabling environment.
- Thought partnership from Andy Brogan at Easier Inc.

#### *People with shared purpose:*

- Lots of people are keen for clearer, simpler measures, and collaborative work across the region.
- Energy, enthusiasm for trying things out.
- Diversity of views, backgrounds (including multiprofessional, clinicians and commissioners), contexts.
- Culture of focusing on people and families, partly derived from the hospice movement
- Enough continuity in the group so not always going over old ground.

#### *Methods:*

- Using small-scale safe-to-fail tests of change has enabled rapid learning.
- Being able to flex approach when needed - learn from what's not working, as well as what is.
- Making the most of nationally available data and dashboards which became available during the course of our work on this.

## | Top Tips

### What are your ‘top tips’ that you think others might find interesting?

- Bringing people together - enough that all the work doesn't fall to just a few, and to enable diversity of perspectives - but not so many that it's hard to make progress.
- Regular meeting or check-ins - every week initially, then every fortnight. Clarity about actions between check-ins too - making use of the spaces between.
- Focus - we kept returning to the core purpose of the group, keeping it simple, not just measuring something because it's interesting.
- Keep going...

## HUMAN LEARNING SYSTEMS



- Some people who were hesitant to engage initially became interested when there were >1000 responses, and they could start to see the value more clearly.
- Good relationships with people across the South West - including in each ICS end of life board - enabled confidence that the intent is collaborative learning and improvement, rather than judgement and blame.

## | Your artefacts

**What 'artefacts' have you created that help you to work in this way?**

*We are currently testing these questions:*

- *How do you feel it's going at the moment?*
- *Why?*
- *Is there anything else that would help to improve the situation?*

This is a link to the Microsoft Form we are currently using to gather responses:

<https://forms.office.com/e/6K72uAETq4>



## | What have you achieved?

**What has adopting an HLS approach enabled you to do?**

- Vital Signs has enabled a focus on what really matters to people (often not the “medical” or “clinical” things we may have assumed).
- Prioritisation of Vital Signs as one of a small number of areas of focus has helped us to reduce work in progress, reducing distraction and enabling more effective working.
- Tests-of-change in practice. People from across the region are learning collaboratively. This is enabling people to learn how safe-to-fail tests-of-change can run, legitimising the approach and helping to normalise this way of working.
- The Vital Signs work has enabled insights in each integrated care system and across the region, creating a foundation for informed conversations with commissioners.
- We are able to work in ways which enable people to thrive and develop healthy working relationships.

This gives an overview of insights from this work so far: [Vital Signs narrative v1.0 - Google Docs](#)



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## | What next?

**What is the next challenge for this work?**

- We are testing the Experience measure with citizens - to understand their views more directly (rather than through the filter of staff views).
- Building on initial momentum to enable learning in practice to become normal.
- Working with commissioners who are keen to explore how commissioning can systematically enable collaborative learning and iterative tests of change.

