

Improving End of Life Care Through Collaboration

Natalie Swann Research Manager
Amanda Stratford CEO

Healthwatch Cornwall
1 October 2019



Session Outcome:

To demonstrate the impact one piece of patient feedback has had on end-of-life care in CloS, & how working with partners was key to creating change.

Session Components:

- Demonstrate a ‘model’ of collaboration with the system
- Highlight role of the Outcomes Framework approach in planning & communicating impact
- Outline our journey to influencing EOL care at NHS STP level



Evaluate impact of previous work:

- September 2017: Evaluation of HC's "A Good Death" conference Jan 2016 and 2015 'Place of Dying' report

Reviewed Current Landscape:

- CQC rated EOL care at acute trust as 'Inadequate'.
- EOL care was not assigned a dedicated work stream within STP
- National audits had highlighted the need for more coordinated, personalised care

Public Feedback:

- HC received numerous concerning accounts of poor experiences of EOL care in Cornwall
- A story landed in our inbox that consolidated the big picture and captured hearts and minds

Evaluation:

- Took evaluation to CloS End of Life Strategy Board (C&loS EoLSB) - agreed a shared understanding of landscape
- Agreed to review progress as a system and to consider how HC could usefully contribute to the improvement of EOL care across the county - independence, credibility

Plan:

- Revised HC strategy 2018-2021
- Agreement with CloS EoLSB for HC to host interagency conference and to
- Conduct research into public understanding of terminology, options and preferences for EOL care
- HC MLMD report recommendations - to drive system-wide plans for improvements monitored via CloS EOL SB
- Led to 'Model of Collaboration'



665 people in Cornwall

Recruitment took place online through a local panel, social media, and Healthwatch's own promotional channels in April 2018

- 9 (1%) with a terminal illness
- 385 (58%) with a family member with a terminal illness
- 285 (43%) carers of someone with a terminal illness
- 361 (54%) supporters of someone with a terminal illness
- 205 (31%) people who had experienced a recent bereavement

- 159 (25%) people with no experience of bereavement or terminal illness



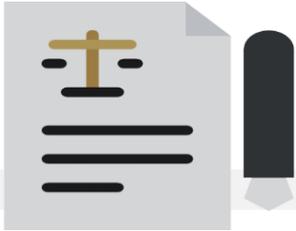
?% of people have spoken to their family and friends about their preferences for end-of-life care

41%

(47% / 21%)

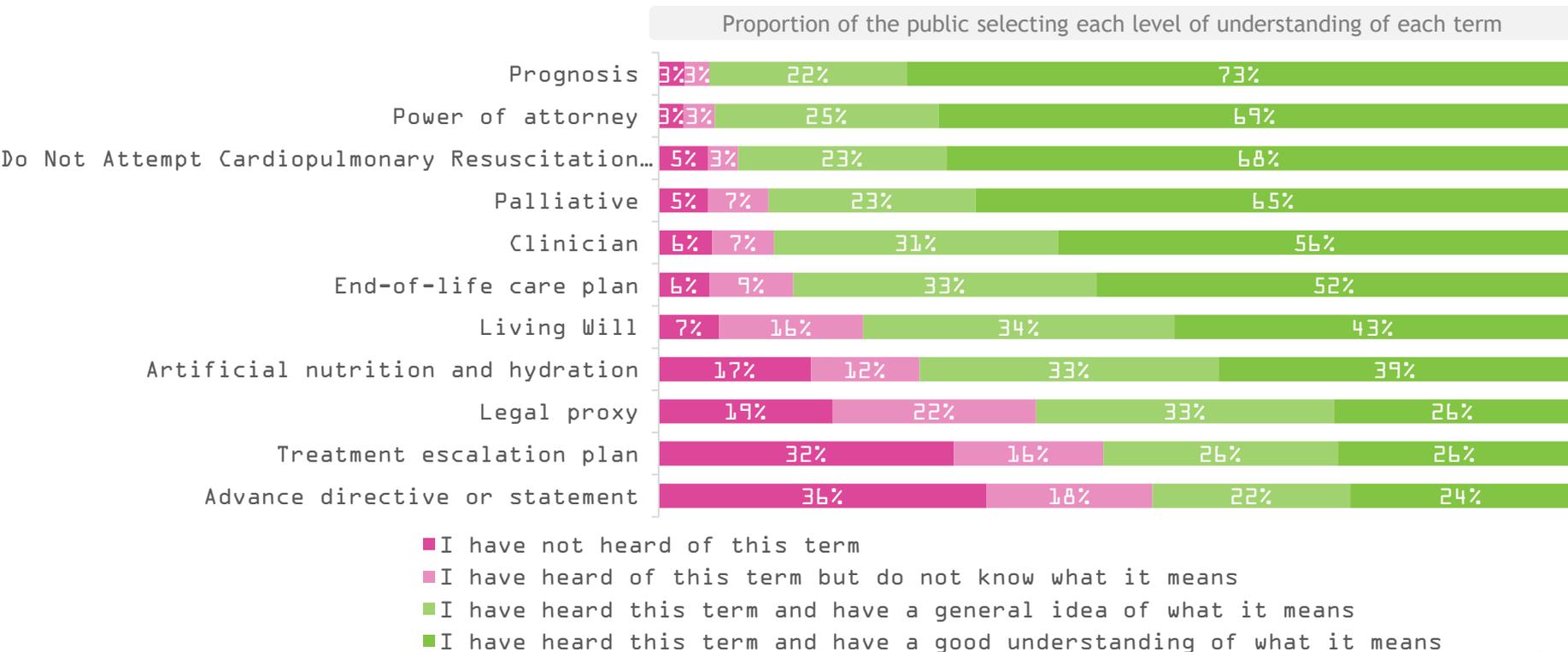


4%



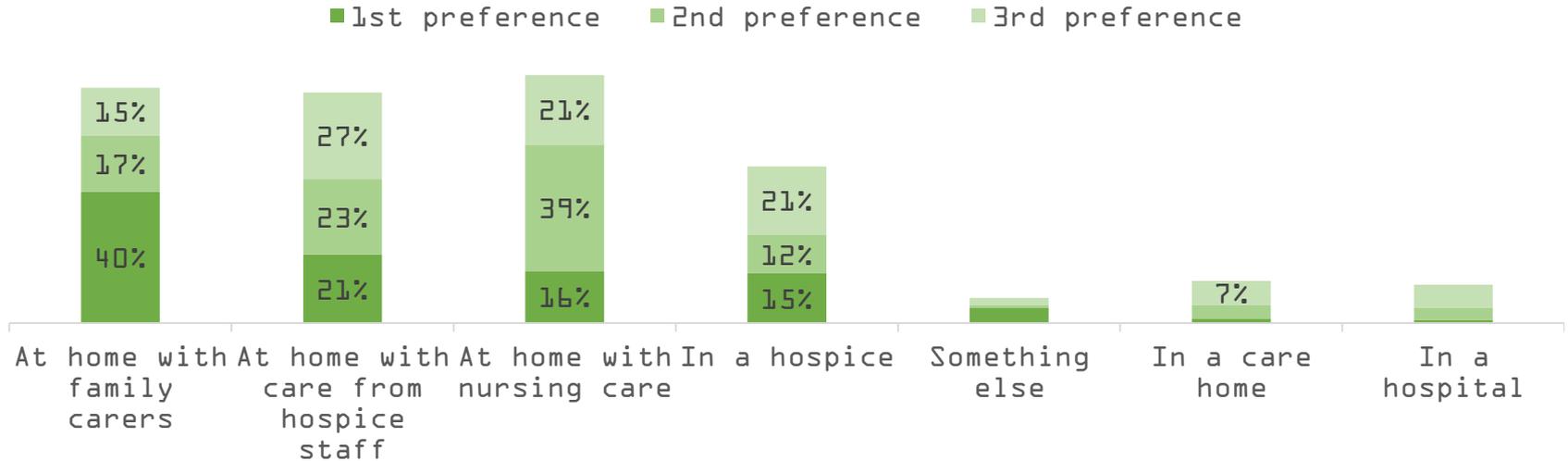
?% of people have an end-of-life care plan

Understanding of many of the terms used in EOL care varies: particularly low for technical terms



The clear preference for end-of-life care is to be at home

Proportion of the public selecting each end-of-life care option as their first, second, or third preference



Alignment with Ambitions for Palliative and End of life Care: access and coordination appear to be areas for improvements

Proportion of the public who agree or disagree that their expectations or experience of care is reflected in each ambition statement

01 Each person is seen as an individual



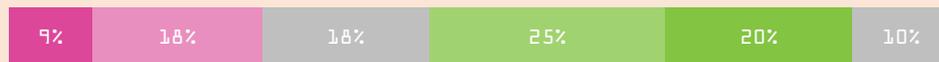
02 Each person gets fair access to care



03 Maximising comfort and wellbeing



04 Care is coordinated



05 All staff are prepared to care



06 Each community is prepared to help



Strongly disagree

Disagree

Neither agree or disagree

'Satisfaction' with diagnosis is variable: 21% dissatisfied - but only 40% satisfied

Proportion of those with experience of terminal illness who are satisfied or dissatisfied with how their/their family members' diagnosis was delivered



- Very dissatisfied
- Dissatisfied
- Neither satisfied or dissatisfied
- Satisfied
- Very satisfied
- I don't know / do not remember

Almost 1/3 of those with a terminal illness disagreed that they understood what they were told about their diagnosis

A 'good' diagnosis is delivered...

- With compassion, kindness and sympathy
- Straightforwardly and honestly
- At an appropriate time and place
- Clearly and informatively, with expectations of a timeframe
- With guidance on next steps, options, and accessing care, and reassurance about comfort and pain
- By someone familiar and trusted
- By someone who has time and can answer questions
- With appropriate preparation (not abruptly)

“She was very straightforward about it, gave a possible time frame, didn’t treat it as a drama, just an unfortunate reality, was encouraging about the time left to my mother.”



“Care home staff were very honest and sympathetic.”

“The doctor was kind, but straight to the point. He did not shy away from the truth of the matter.”

“Because I knew everything possible was being done to make my family member's last days as comfortable as possible and pain free.”

A 'bad' diagnosis is delivered...

- Blunt and without compassion
- In a rushed manner, without opportunities to ask questions
- In an inappropriate setting (e.g. on a ward)
- Without family present
- When it is not necessary or asked for
- Without advice on next steps or options for care
- 'Too late'

"It was delivered in a cold and matter of fact way with no compassion. The doctor might have easily been saying she had an in growing toenail!"



"Not upfront about how much time and no advice on next steps."

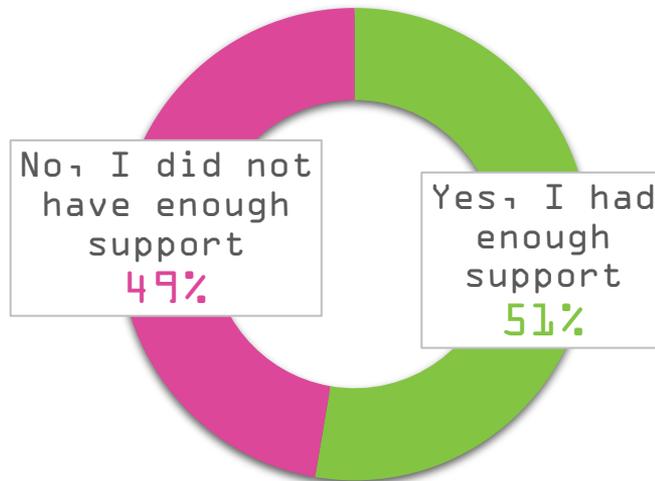
"They treated my father like an idiot. They didn't listen or use respect."

"It wasn't explained fully or in a comfortable setting. I was told in a doorway to an office very briefly and very rushed. I wasn't asked if I fully understood what I was told."

Almost half of carers or supporters of someone with a terminal illness do not feel they had enough support

Carers and supporters

Proportion reporting that they received enough support as a carer or supporter of someone with a terminal illness



Almost half of those who were bereaved did not feel they had enough support

Proportion of bereaved relatives reporting that they received support after experiencing their bereavement



Also identified an unmet need for support following the immediate bereavement period >6-12m

While 50% were satisfied with the end-of-life care their family member received, 29% were not

Bereaved

Proportion of bereaved relatives who were satisfied or dissatisfied with the quality of care that their family member received during the end of their life



- Very dissatisfied
- Dissatisfied
- Neither satisfied or dissatisfied
- Satisfied
- Very satisfied
- I don't know / do not remember

“It's all been such a muddle of financial and emotional turmoil. It's like a bomb exploded in our midst and we were all flung apart never to really find our way back together again. It's the aloneness of all the choices and decisions, coping with breakdowns of people, homes, appliances, with only yourself to refer to. The absence of that lifelong partner and father to, is a huge emotional hole in our lives to this day”

“I believe that we should all be able to choose how and when we die if there is no chance of a recovery to the point of enjoying life. I never want to be a burden to my family or the health and care services. It seems to be that there is a consistent lack of joined up thinking about end of life care mainly because we don't discuss it often enough in the public domain. Hopefully, this will be the beginning of a change.”

Research as part of baseline: Key Messages

- **Public education:**
 - Encourage **conversations** about death and dying, and document **preferences**
 - Ensure the public know they have **choices** on what happens to them
 - Education on the **language and terminology** when talking about end of life care
- **EOL Care:**
 - Support **provision of end-of-life care at home** where possible, whether with family, nurses, or hospice staff
 - Ensure care is **dignified**, as **pain-free** as possible, and provides **peace and comfort**
 - Target the key ambitions that performed less well in Cornwall; **‘each person gets fair access to care’** and **‘that care is coordinated’**
- **Improve the experience of diagnosis with a terminal illness**
 - Hospital doctors most often deliver diagnosis, with hospitals often the location of unsatisfactory diagnosis: stress importance of: **tone, care and comfort**, give timeframe; **right: place, people, and appropriate time**
 - clear about next steps
 - **Understanding the diagnosis:** improve communication and check understanding
 - Provide families and GPs with the **tools and skills** needed to provide support

Research as part of baseline: Key Messages

- **Recognise and support carers and supporters:**
 - they are common in the community, providing very frequent care and many types of care
 - but **not getting enough support**

- **Increase the support for those who are bereaved:**
 - Particularly at the ‘middle’ of their journey (6-12m); and with private, legal, financial affairs; information provision; and support for carers
 - Give family, friends, and funeral directors tools and support needed to support those who are bereaved = “Compassionate communities”

Maggie and John's Story: The catalyst for change

Feb 2018 Maggie emailed, but did not want to complain:

"I believe that the way my husband was treated in the last months of his life in the acute and community hospitals was not acceptable...."

HC Webform: What do you think can be done to fix things or share good practice?

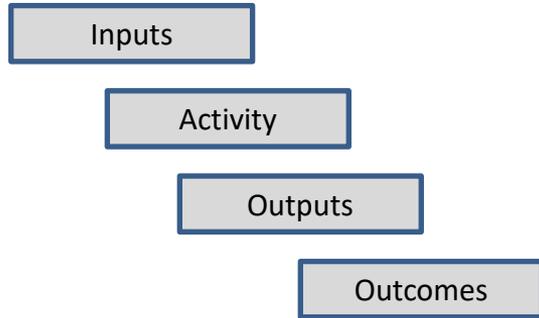
"Better training in dealing with end of life care. More training in how to keep families informed and to ensure that the family understands exactly what is happening. Better liaison between hospital and social services."

Transcript:(ask Healthwatch Cornwall - please feel free to use the film/transcript)

<https://www.youtube.com/watch?v=RI0LnP6aLpQ>



Outcomes - the basics



- The inputs are the **resources** you have to do your work.
- The activities are **what you do** (e.g. carry out research, attend meetings),
- The outputs are **what you deliver** (e.g. number of reports issued or numbers of people attending an event).
- The Outcomes are **the difference** or key **changes** made as a result of your efforts.

What's an outcome?

This exercise aims to help people get a working definition of outcomes and clarify the key terms.

Exercise

<i>Inputs are the resources you have and need to do your work.</i>	<i>Activities are what you do – what you organise and do.</i>	<i>Outputs are your 'deliverables' – what you produce.</i>	<i>Outcomes are the results of your work – the difference you create or influence.</i>
--	---	--	--

Listed below are eight items. The task is to identify which are outputs or outcomes.

1. Good local press coverage of a recent report.

3. Changes to an appointment system

5. An action plan agreed to improve referral systems.

7. A commitment to train all front line staff in autism.

2. HW representation on a key policy group

4. Setting up a mental health users group

6. A report on patient experience of A&E

8. A trust now actively engages carers in future planning

Where would you put each item

Inputs	Activities	Outputs	Outcomes

Inputs	Activities	Outputs	Outcomes
		1 – press coverage 2- HW representation 5. Action plan – referrals 6.. Report on A&E experience 7. Commitment to train staff	3. Changes to appointments 4. Setting up a MH users group 8. A trust now engaging carers

Some points to consider:

- The output is what you do and deliver – the outcomes is the result.
- The outcomes are about the difference you make (or contribute to) for people and communities.
- Outputs are usually visible and easy to count whereas outcomes are often medium to longer term. The outputs are in your control – you manage them. Outcomes often depend on others.

The language

Outputs	Outcomes
Outputs are usually in an active and easy to measure language: <i>“We will attend x number of meetings”.</i> <i>“We will produce x number of reports”.</i> <i>“We will manage x number of complaints”.</i>	Outcome language is more about the results or difference made: <i>“Services for younger parents are improved”</i> <i>“People from BME communities are more engaged in service planning.”</i> <i>“Local people are better able to influence service planning”.</i> <i>“That the local action plan for the NHS Long Term Plan is informed by the views and experience of local people”.</i>

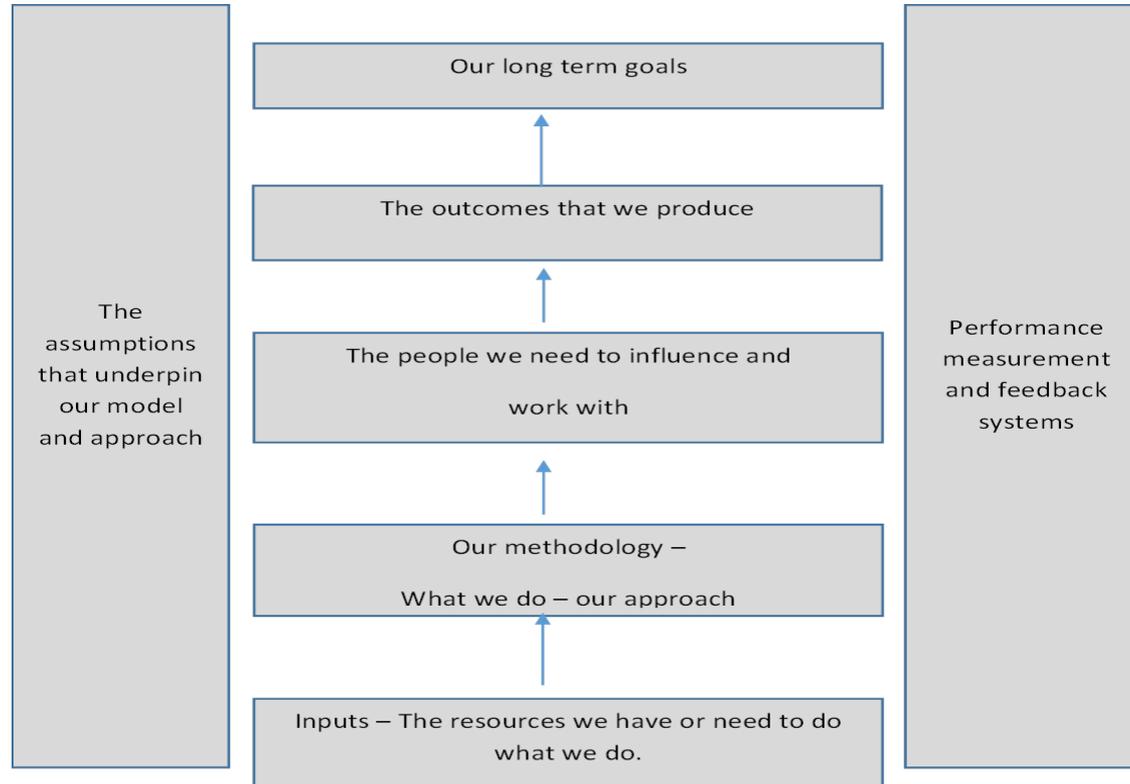
Theory of change:

- a useful and thoughtful way of clarifying what their organisation is trying to do
- sets out, ideally on one side of paper, the model behind the organisation

Can be used to:

- Explain to others your **purpose, outcomes** and **thinking** behind your approach.
- Show how what you do **creates change**.
- Check that people see and understand the **bigger picture** behind what they do.
- Identify any areas or assumptions that may need rethinking or challenging.
- The exercise can be used at both an **organisational** and **project level**.

Theory of Change Model



Measuring outcomes

- Can be challenging.
- Easier to count outputs as they are usually obvious and tangible.
- Outcome measurement requires a different approach:

• Outcome

• Use a

• Measure



- Look out for unplanned outcomes - might not have been planned, but are of value.
- Build the measurement into the systems and processes that you already have.
- Outcomes are usually about change - people being able to do things that they couldn't, learning new skills or changes in how the bigger system operates. Record the changes you see - from early outcomes to longer term sustainable change.

EOL Care Improvement Plan for Cornwall

Assumptions

- Research: People will want to share their views and we are asking the right questions.
- People understand the purpose of this work and in agreement with 'baseline assessment
- Conference attendees - right number right people
- Decision makers want to engage, listen and act.
- We have enough capacity, the right skills, budget etc
- We can deliver key milestones in the timeframe.
- We are engaging with the right stakeholders
- HC respected as credible & independent

Long-term goal

- **Improved end-of-Life Care in Cornwall:** "We would like everyone to receive high quality care, delivered compassionately and with dignity, by the right person, with the right skills at the right time. By doing so, we hope this will ensure people at the end of their lives and those close to them, will experience a calm, peaceful and dignified death where possible"
- **To facilitate a cultural shift** to de-medicalise death within our community and enable better, more personalised planning and care

Outcomes

- Providers/managers/staff have a greater understanding of public experiences, options and preferences for EOL care & public understanding of terminology, in order to improve services accordingly
- HC seen as key partner to improving services & public experience across the system.
- The CloS EOL Strategy Board priorities & strategy are informed by the views and experiences of local people.
- The public experience better, more personalised care in more compassionate communities
- Staff and public education is shaped by our work

Methodology

- Host EOL Conference for professionals
- Conduct public research and analysis reaching diverse audience -
- Public facing campaign to encourage conversations & EOL planning
- Develop resources to support EOL planning with providers and public
- Engage with key stakeholders including buy-in from EOL Strategy Board
- Contribute to the projects that are born out of this work

Inputs/resources

- Staff and volunteers.
- Develop public campaign
- Baseline data: CRM, public research, staff/provider feedback, local/national audit, system knowledge
- Survey and roll out via panel and SM
- Conference: budget, time, staffing, materials
- Meetings & projects attendance
- Film

Measures

- 600+ survey responses.
- Rise in public understanding of options
- ACP completion levels
- Attendance of 80-100 range HCPs at MLMD conference.
- EOL film
- Report post conference respected and has influence - adoption of recc's
- Materials: EOL planning, Education leaflets, resources, charter
- Engagement from all providers and EOL SB
- Public facing campaign
- Information shared across the local health and social care system.
- Rise in positive public feedback
- Sweeney project KPIs

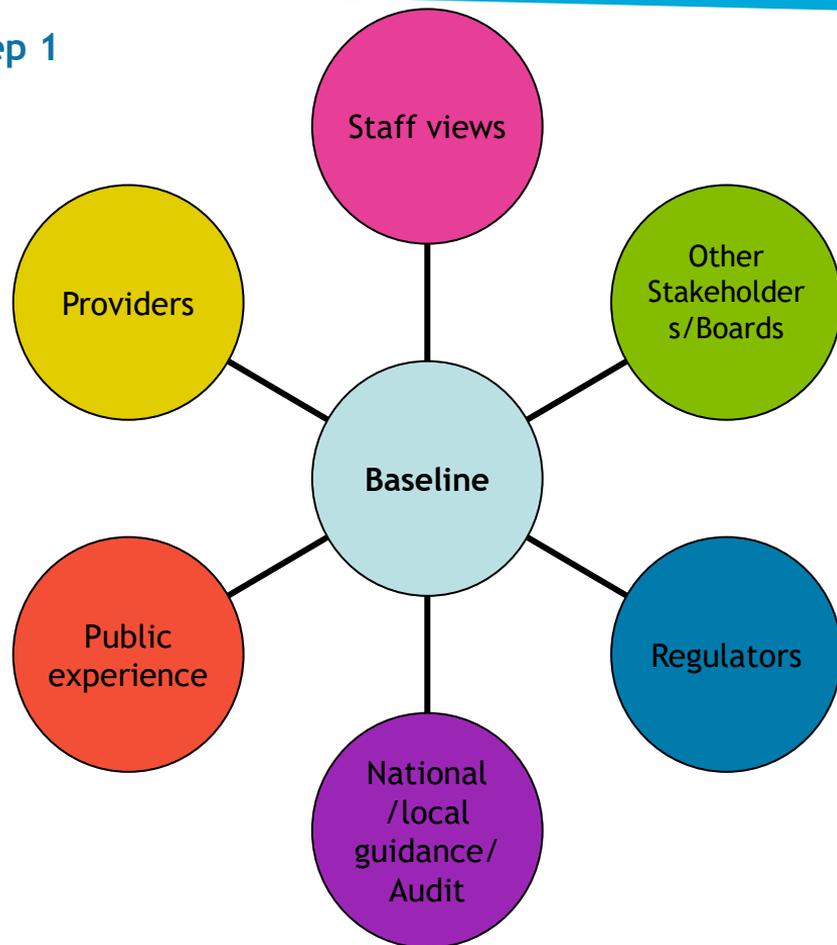
Background to the Model:

- CloS EOL SB highlighted our work as a potential 'model' for how other systems, services, providers should work in collaboration with with HC in order to drive positive change and QI

Reviewed with key stakeholders - Cornwall Hospice Care:

- Review of last 18 months work resulting in HC being confident recommendations from report are being actioned and seen as key partner to improving services & public experience across the system.

Step 1



What did we do?

Step 1: Knowledge baseline: Evidence

- Baseline: Triangulation of views and opinions giving a CLEAR PICTURE from a variety of perspectives CQC, staff's views, evidence of public/patient opinion, HC research

Step 2: Agreed a shared understanding

- Sought assurance - all stakeholders owned a common understanding of the current state of play

Step 1



Topical Patchy
Random Hospices Mindful
Poor Supportive
Disempowering Compassionate
Slow Kind Humbling Caring
Disjointed
Choice Varied Uncordinated
Limited Loved Underfunded
Sharing Challenging
Fragmented Lottery
Emotional Disconnected
Misunderstood
Dignity

Step 3 Application: Applying the new understanding to ask what's working well and what do we need to improve?

- Appreciative Inquiry/Strengths based approach to questions to build on positives

Step 4 : Agree actions, goals and desired outcomes: Agree local service development plans/priorities and outcomes

For us this included

- Building on: EOL Research to gain public understanding of terminology, options and preferences
- Building on: EOL Conference for professionals informed by research
- Agree actions for all stakeholders to achieve CloSB EOL SB priorities for EOL care (post research/conference):
 - To raise public awareness and improve EOL education and training
 - To improve EOL care planning in advance
 - To ensure people and professionals can access the right care and support at all times of day and night

Step 5 Evaluation: Evaluating decisions, actions, progress (ongoing)

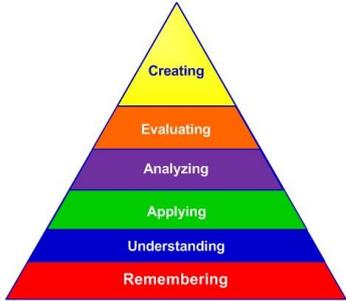
- Currently reviewing CloS EOL SB strategy and priorities in light of so many new developments, changes and technology
- Many new outputs and outcomes across the system
- Ongoing projects being implemented - Sweeney Project as one working example
- Growing/continuing sense of energy and commitment from all stakeholders

Step 6 Legacy: Achieving outcomes and long term goals

- Aim of leaving a legacy of improved care
- Ongoing evaluation of where are we now
- How do we know when this has been achieved?
- How do we communicate outcomes



Blooms Taxonomy - Revised



Guiding Principles:

- Always looking at it from a multifaceted approach
- Culture of honesty - difficult conversations again
- Healthy conflict and honest conversations
- Solution orientated
- Keeping patient at the centre
- Plan for dealing with difficult conversations respectfully and recognising the value of each other
- Clearly identifying what success looks like
- **Independent Healthwatch presence throughout**
- Question - are we there yet? - Review perspectives held at the start and see what the new view/understanding is
- Research - test - do - evaluate

What made it work?

- Stories give energy - win hearts & minds
- Eureka moment - shared understanding and commitment
- Created a common vision - Spend time on this
- Passionate leadership - clarity
- A body of broad champions from across all stakeholders - had to work hard on this but it was a vital part
- Had practical people on the 'bus'
- Recognition it takes time
- Identified barriers and mitigated before starting as much as possible - this included on staying on track
- Planning difficult conversations in - identifying and preparing for elephant traps

Activity:

Have a think about a key area of focus, project, concerning feedback, bubbling issue - discuss in groups and feedback the following:

Consider: (15 minutes to discuss - 10 minutes to feedback)

1. How this model could work at a small project or wider priority level
2. Be prepared to share an example or your thoughts
3. You may wish to consider:
 - Who are your stakeholders?
 - What would you need to consider at each rung of the model?
 - What outcomes do you want to achieve
 - Think about the 1. Guiding principles and 2. What might make it work
 - How will you communicate outcomes



Outputs:

Included some of the following:

- Public campaign - celebrity endorsement #Littlelifeconversations
- Provider mandatory training - Maggie & John film
- BBC local coverage
- Conference 100 staff
- Report - recommendations
- Advance decision card, shaped Advance Care Plan & patient leaflet for advance planning
- NHS Parliamentary Award Maggie Vale
- EOL Patient Charter
- Educational events
- Chief Exec apology!

Outcomes:

- Providers/managers/staff have a greater understanding of public experiences, options and preferences for EOL care & public understanding of terminology, in order to improve services accordingly
- HC seen as key partner to improving services & public experience across the system.
- The CloS EOL Strategy Board priorities & strategy are informed by the views and experiences of local people.
- The public experience better, more personalised care in more compassionate communities
- Staff and public education is shaped by our work

Session Outcome:

To demonstrate the impact one piece of patient feedback has had on end-of-life care in CloS, & how working with partners was key to creating change.

Session Components:

- Demonstrate a 'model' of collaboration with the system
- Highlight role of HE Quality Framework in planning & communicating impact
- Outline our journey to influencing EOL care at NHS STP level



Maggie Vale - Maggie and John's Story - Outcomes... Legacy?

Since the film was incorporated into mandatory training, Sue Adams, EOL Care at Royal Cornwall Hospitals:

"Maggie and Johns story has made an inestimable contribution to facilitating a changing culture within the acute trust. It brings together so beautifully and succinctly the key messages we want to convey. Playing the film very often changes the mood within a room with messaging around recognising dying, good communication and shared decision making moving from abstract principles into tangible reality.

The response to the film is uniformly one of compassion, with participants on occasion moved to tears. Sometimes people feel angry, sometimes ashamed but most often there is sadness, reflection, contemplation and admiration. I have had participants say that they have gone home and played the film to their families, I feel there can be no better commendation than this.

The film was incorporated into mandatory training last September. In the months since it has been shown to literally hundreds of healthcare professionals, doctors, nurses, physio's etc. Maggie can be assured that we have the utmost commitment to doing justice to her experience."

- Maggie Vale, who very sadly is now herself terminally ill, has been approached by doctors, HCAs and nurses while an inpatient in the hospital, who wanted to tell Maggie about the impact and difference 'Maggie and John's film' has made to them.

Thank you

