



Public Engagement on the Wiltshire End of Life Care for Adults Strategy 2017-2020

An
independent
voice for the
people of
Wiltshire

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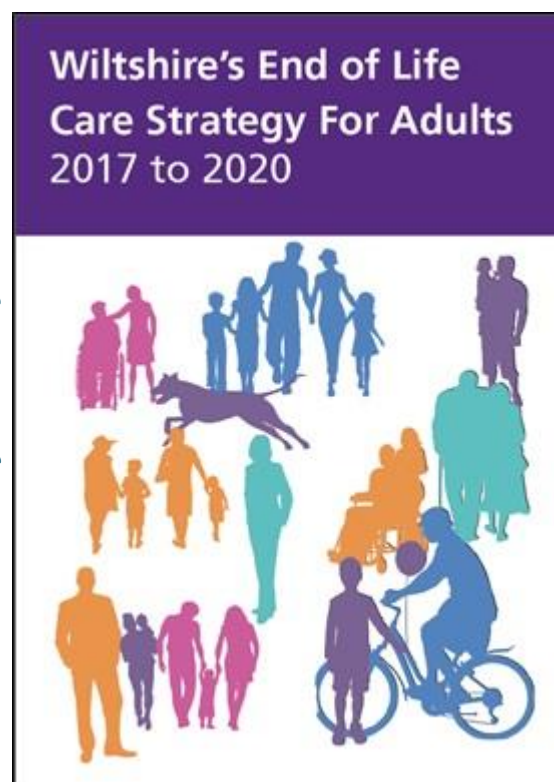
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Background

About four thousand people die each year in Wiltshire. Most are older people who had been living with a chronic condition. Compared to ten years ago, more people in Wiltshire are dying at home or in a hospice, and fewer in hospital. Care to support people at the end of life is provided by a range of services including hospitals, hospices, care homes, pharmacies, social care agencies, charities, GPs and community services, as well as unpaid carers.

NHS Wiltshire Clinical Commissioning Group (CCG) and Wiltshire Council are refreshing the Wiltshire End of Life Care Strategy, and are interested to hear what people think is important in end of life care. This will help them to develop their plans for end of life care in Wiltshire.

Healthwatch Wiltshire was asked by NHS Wiltshire CCG and Wiltshire Council to help gather public feedback on the draft strategy. The feedback will be used to shape the plan for delivering services in the future.



What we did

1. Pre-engagement

The draft strategy was shared with members of the Healthwatch Wiltshire readers' panel (volunteers who read and comment on documents). Nine volunteers fed back with a variety of comments, covering readability, content and potential areas for further work. This feedback was shared with the strategy authors, and was used to inform the version of the strategy used in the wider public engagement.

2. 'Starting a Conversation' events

Healthwatch Wiltshire facilitated three public events called, 'Starting a Conversation about End of Life Care'. At each event, a representative from NHS Wiltshire CCG explained the strategy and plans for end of life services in Wiltshire and answered questions from members of the public. There was also an opportunity for people to feed their views and experiences into discussions in small groups and a chance to visit information stalls held by different organisations which deliver services and support to Wiltshire people at the end of their life (and their families).



“Your voice is our voice”

3. Online questionnaire

An online questionnaire was hosted on the NHS Wiltshire CCG website between 16th November and 13th December 2016. People who were unable to attend the events were encouraged to complete the online survey.

4. Other opportunities to provide views and experiences

Healthwatch Wiltshire work with Dorothy House Hospice on user involvement. The User Advisory Group kindly agreed to look at the strategy and how it links with that of the hospice. Salisbury Area Board Health and Wellbeing Group also provided its views about end of life care. We also examined issues around end of life care raised with us by members of the public as part of our ongoing monitoring of the quality of services.

Who we spoke to

We heard from 91 people in total.

We held public meetings in Salisbury, Royal Wootton Bassett and Bradford on Avon in November 2016. These were attended by members of the public and professionals from various organisations providing services to people at the end of life.

Table 1: Breakdown of engagement numbers

Venue	Members of the public	Health and Social Care professionals	Healthwatch Wiltshire staff and volunteers
Salisbury	9	8	5
Royal Wootton Bassett	7	10	8
Bradford on Avon	5	10	7



5 people fed back on the strategy and end of life care in the county through the online questionnaire.

10 members of the Dorothy House User Advisory Group reviewed the strategy and fed back to us. 7 members of the Salisbury Area Board Health and Wellbeing Group also fed back about end of life care.

“I feel better informed and have a better understanding of the objectives of the strategy.”

Engagement participant

We asked people these questions:

General

- If you are at the end of life, or caring for someone who is, what is most important to you?
- What needs improving now?
- What support does an unpaid carer caring for someone at the end of life need?

Format of strategy

- How easy is the strategy to read? Is it clear?
- Do you feel more informed about end of life care after reading the strategy/ coming to the event today?

Content of strategy

- Is what Wiltshire Council and NHS Wiltshire CCG are doing, and intend to do, right to ensure good end of life care in Wiltshire?
- In terms of the strategy and end of life care, what else could they be doing in the next 3 years? (Do you think there is anything missing from the strategy?)
- Are the success measures right for the strategy? Anything else they should measure?
- What actions do you think need to happen for the strategy to be successful?

Other feedback

- Do you have any other comments on the strategy?
- Do you have any other comments on end of life care?

We used our wider and previous engagement to add to the general feedback about end of life care. People raise things that they feel are important or missing from current services with us through our monitoring of the quality of services and investigations into particular topics, such as dementia.

What people told us

1. Feedback on the strategy format

There was mixed feedback on the format of the strategy. Some people felt that it was clear and well presented, while others found it more difficult to read. This may reflect the variety of people who participated, some members of the public and some members of health or social care organisations.

A number of people questioned who the strategy was aimed at, and did not feel that the public was the target group for this document. Acronyms and jargon were not always explained.

"It is a nicely presented, clear document."

Engagement Participant

“Too much management speak.”

Engagement participant

Members of the public felt that it was written from the perspective of professionals and providers, viewing the public as patients, rather than everyone as people.

The size of the document was mentioned as too large by a number of groups and individuals, with one describing it as “overwhelming”. Participants also felt that it was difficult to look at online and assumed it would be expensive to print out. Participants said that they wanted a simplified or easy read version or summary. They said what they would find most useful would be a two-page document which included signposting to services (based on what was offered through the strategy) and phone numbers to

access them. The ‘Strategy on a page’ (page 6 of the draft document) was designed to be an accessible, simple to read summary of the strategy. Some groups liked this section and found it helpful in understanding the strategy, while other people felt that this was too wordy and did not contain the information that they would want from a public version.

“A short easy read version for the public is needed.”

Engagement participant

“The strategy is just a professionally presented document laying out lots of good intent but with little accountability... I notice that it is not marked “draft”... I wonder if anything we say will be taken into consideration?”

Engagement participant

Feedback was also received about the way some of the information was laid out. For example, white writing on a colour background can be difficult for some people to read, particularly people with visual impairments. Some participants felt that the graphs were difficult to understand. (All future Healthwatch Wiltshire reports will take this into account).

2. Feedback on the strategy content

People felt that the strategy lacked information on what would happen next, including targets and concrete actions, and who would be accountable for these. At the meetings, the commissioners emphasised that the public feedback would be used towards the creation of an implementation plan. However, there was an expectation from the public that a strategy would include this information.

“Overall the Wiltshire end of life strategy lacks warmth and a simple vision statement.”

Engagement Participant

“The Wiltshire vision is clear and reinforced throughout the document.”

Engagement participant

Members of the public thought that there was a lack of focus on unpaid carers, although reference is given to the Carers Strategy.

Respondents felt that some consideration of people from different cultures, religions and those without a religion would be beneficial.

3. Feedback about the success measures or “what we want to achieve”

“Success measures should be measured by an impartial outside body.”

Engagement participant

Most participants agreed that the goals laid out in the strategy as “what we want to achieve” (page 6 of the draft strategy) were admirable and good goals. However, there were questions about how they would be prioritised, and delivered.

Questions were asked about how improvements could be made given the current shortages of trained staff.

People thought that the goal of increasing the number of advanced care plans and treatment escalation plans was only worth-

while if the use of them was also monitored. They felt that the true test was whether they were used and successfully enabled peoples’ choices to happen. They considered the care to be more important than just having the paperwork in place.

A reduction in complaints about providers of care involved in end of life services was also suggested as a goal for the strategy.

“The emphasis should be on people, not policy.”

Engagement participant



“All is dependent on the communication skills, kindness and dedication of the staff delivering the end of life care.”

Engagement participant

“The strategy is actually rather short on strategic actions to be taken to achieve the stated goals.”

Engagement participant

“It was good to read the patient/family/carers are the focus and especially they would continue to listen to the needs of the local population.”

Engagement participant

4. What is important to people at the end of their life?

People who took part in the engagement identified a number of areas which were important to people who were at the end of life and their unpaid carers:

- Symptom control (especially controlling pain).
- Being treated with respect and dignity.
- Choice - about the location where end of life care is provided and ensuring individual wishes around particular care options are respected
- Information - provided in an accessible manner for patients and carers, covering what is available (that the person is eligible for) and what they can expect. Every group said that online information was insufficient, and hard copy and face to face information was also vital.
- The importance of having early discussions about individual wishes, and decisions such as Power of Attorney, and Advance Care Planning. This was especially mentioned in relation to people who are living with dementia.
- Support for unpaid carers and family members, including a single key person supporting a person at the end of life and their unpaid carers, coordinating all the professionals involved in care and able to signpost to other sources of support.
- High quality staff with end of life training and the ability to put it into practice.
- Continuity of care from clinical professionals and domiciliary carers.
- Good communication between professionals and with the patient and family.

Many of these are areas that fall within in the draft strategy priorities. However, these are also combined into the aims in the current (2014-2016) strategy. We know that there are people for whom these aims are not always achieved. People who took part in the engagement identified areas that they thought could be improved:

1. The 'visibility' of death and the societal view of dying, and the encouragement of early discussions about peoples' wishes and options;
2. Recognition that someone is coming to the end of their life, so information/services/ support can be accessed without delay;
3. Availability of domiciliary care, and responsiveness of systems to adapt to reflect changing circumstances requiring changes in the amount of care (both especially raised in relation to Continuing Health Care, but also more generally);
4. More communication and collaboration between services and less duplication across services;
5. Communication with family members and dying patients, especially those with disabilities or who are otherwise potentially isolated;
6. Patient and carer access to information held about them by professionals;



7. The number of people with dementia referred for end of life or palliative care services;
8. Waiting lists for services, such as bereavement counselling;
9. Availability of end of life and caring skills training for unpaid carers (for those willing to be involved in this role);
10. More support for unpaid carers so that they can spend time with the dying person, not spend their time and energy doing the caring tasks (for those who want it);
11. Support locally for carers, as travelling long distances to access support groups deters people who don't want to spend a lot of time away from their loved one and the effort of travelling was perceived as undoing any of the benefit from support groups;
12. Inconsistency of services across the county, with not everyone able to access all services;
13. Access to medications, including out of hours, especially for people who are without their own transport or otherwise unable to go to pharmacies themselves, and information on pharmacies stocking end of life medications;
14. Inclusion of professionals from beyond health and social care as part of caring communities, such as religious leaders (where appropriate), housing staff, postal workers and solicitors involved in end of life planning;
15. Anticipatory prescribing of equipment as well as medication.

"It reads as being closely aligned to national guidance."

Engagement participant

Some of the feedback we received related to areas beyond Wiltshire, for example the difficulties people face in completing national forms to claim benefits, and the content of national media. Representation of resuscitation in films and on TV may create unrealistic expectations of success. The cost of arranging Lasting Powers of Attorney were also mentioned.

Local people strongly felt that people needed to have earlier conversations about death and dying, within families and in the wider community. Suggestions were made of having end of life champions in local communities.

There were also concerns that any changes happening in health and social care (either within the strategy or beyond it) were more about cost-cutting than about patient welfare. People felt unclear as to how the strategy fits with other developments in health and social care, such as Sustainability and Transformation Plans. For those attending the meetings, this was explained in response to questions. People were interested where funding came from for end of life care. Concerns were raised as to how parts of the strategy could be implemented until personal health budgets were in place, especially as it was felt that these were "in their infancy".

"Make the strategy more positive and less verbose."

Engagement participant

Positive feedback was received about hospice provision, including the outreach and hospice at home services.

Feedback from participants at the meetings included how useful they found the information about services that was available from the information stands.

Challenges

The timescale for this project has been tight. Delays in preparing the draft strategy and online questionnaire meant we weren't able to publicise the events and opportunity to feedback online as much as we wanted. We invited stand holders and asked our volunteers to share information in their communities before the strategy was available, and started publicising to the voluntary and community sector and the wider public a fortnight before the first event, before the survey was online. Obviously, this is not ideal, as people who may have wanted to feed in may not have been able to do so at a convenient time. This may have contributed to the low response rates.

Many of the people who participated through the engagement had not had the opportunity to read the strategy in advance. This meant that they were not able to feed back in depth on the content and format of the strategy, but were still able to share their views about end of life care and what is important to patients and unpaid carers.

Recommendations

1. Commissioners should consider the priorities and concerns raised by the people involved in the engagement when finalising the implementation plan.
2. Once the strategy and implementation plan has been finalised, commissioners should produce a short, accessible document for the public. This should also include signposting information for patients or carers to access services.
3. Future engagement on health and social care related strategies needs to consider how to make the strategy easily available to participants in advance of engagement, to give people an opportunity to read it properly and then be able to comment.

Acknowledgements

Many thanks to the members of the public and organisations who attended the events and shared their feedback. Further thanks to the organisations who shared information at the events, and who publicised the project. We are also grateful to the organisations who invited us to their events to discuss the strategy. Thanks to the members of the Healthwatch Wiltshire Readers' Panel for their comments and Healthwatch Wiltshire volunteers who helped facilitate the events.

Definitions

End of life

“People are considered to be approaching the end of life when they are likely to die within the next 12 months, although this isn’t always possible to predict. This includes people whose death is imminent, as well as people who:

- have an advanced incurable illness such as cancer, dementia or motor neurone disease
- are generally frail and have co-existing conditions that mean they are expected to die within 12 months
- have existing conditions if they are at risk of dying from a sudden crisis in their condition
- have a life-threatening acute condition caused by a sudden catastrophic event, such as an accident or stroke”.

[Source: NHS Choices⁽¹⁾]

Unpaid carer

Healthwatch Wiltshire uses the term unpaid carer to describe anyone who provides care to another person, outside of a professional role. This includes adult carers who are caring for another adult (such as a spouse, relative or friend), parents who are caring for a child who has additional health needs, and young people (including children) who have a caring role.



About Healthwatch Wiltshire

Healthwatch Wiltshire is the independent consumer champion for health and social care in Wiltshire. It has an important role in assessing the quality of health and social care services today and influencing the design of services for tomorrow. We want to make sure that the people who use these services have a say in how they are shaped and that their overall views and experiences are heard and taken seriously.

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Wiltshire

⁽¹⁾ www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx

Why not get involved?

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