Feedback from the Vale of York patients, public and partners around current experiences of end of life care

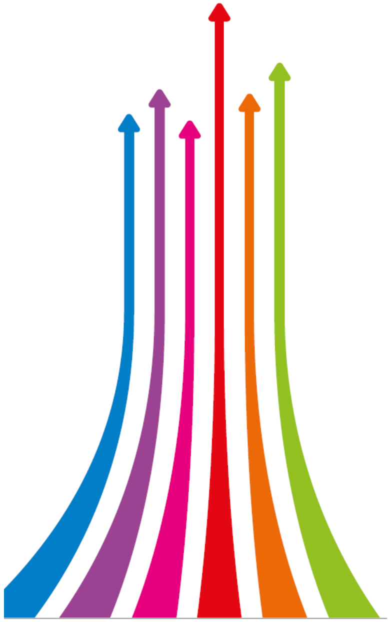
May-November 2018

NHS
Vale of York
Clinical Commissioning Group

Experience of End of Life Care

We used the six ambitions for palliative and end of life care to benchmark where we are as a system

- **Each person is seen as an individual**
- **Each person gets fair access to care**
- **Maximising comfort and wellbeing**
- **Care is coordinated**
- **All staff are prepared to care**
- **Each community is prepared to care**



Who have we spoken to?

Surveys (August-September 2018)

- Patient & carers groups
- Stakeholder & internal e-newsletters
- Hospital e-newsletters
- Professionals: solicitors & funeral directors

Focus groups and engagement sessions

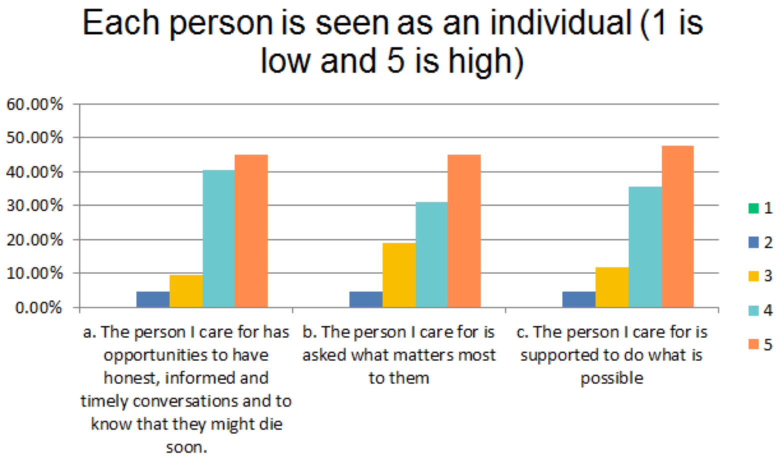
- Clinicians – hospital, hospice, community services, GPs
- Care homes and carers groups
- St Leonard's hospice
- Dying matters week
- Public session

Survey response highlights (69 total)

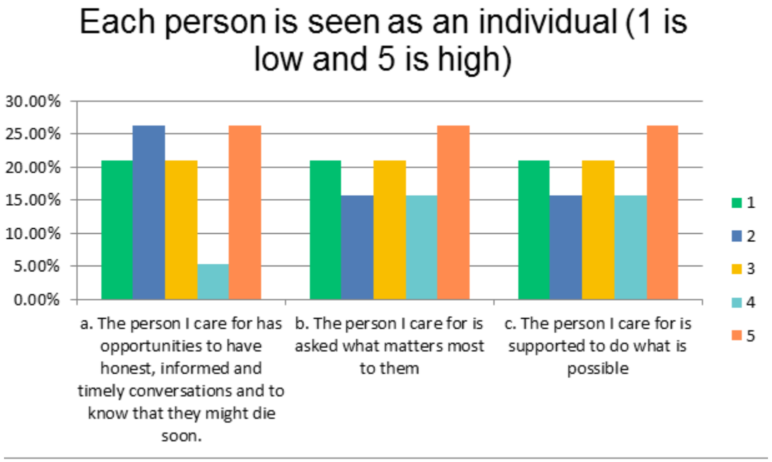
- Carers, family and friends felt less strongly than clinicians/professionals and service users in response to the questions
- 45% of clinicians/professionals and 50% of service users felt strongly that the person being cared for was asked what matters most to them. However, only 26% of carers, family or friends felt strongly
- A high proportion of carers, friends and family did not feel the person they cared for got fair access to care (58%)
- Service users felt most strongly that their care was co-ordinated (58%) in comparison to carers family and friends (26%) and clinicians/professionals (22%)
- All categories of respondents responded strongly to the view that all staff were prepared to care (87% service users, 94% clinicians/professionals and 66% carers, family and friends)

Each person is seen as an individual

Clinicians and professionals


Each person is seen as an individual (1 is low and 5 is high)

Family, carers and friends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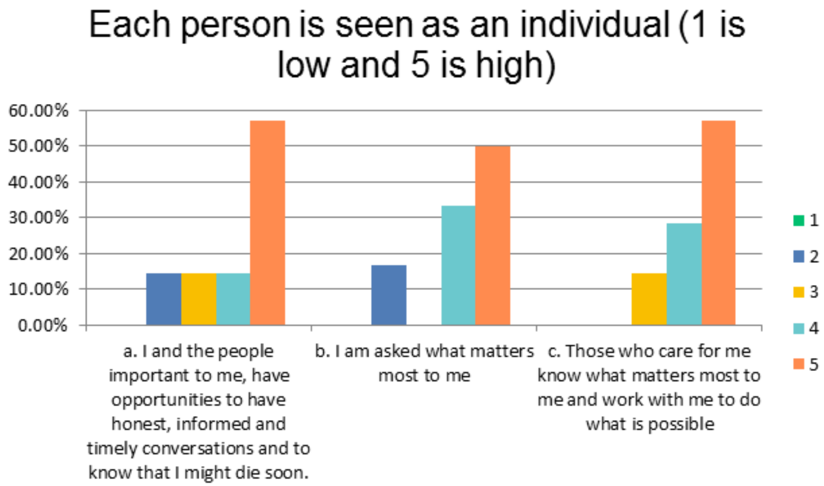
Service user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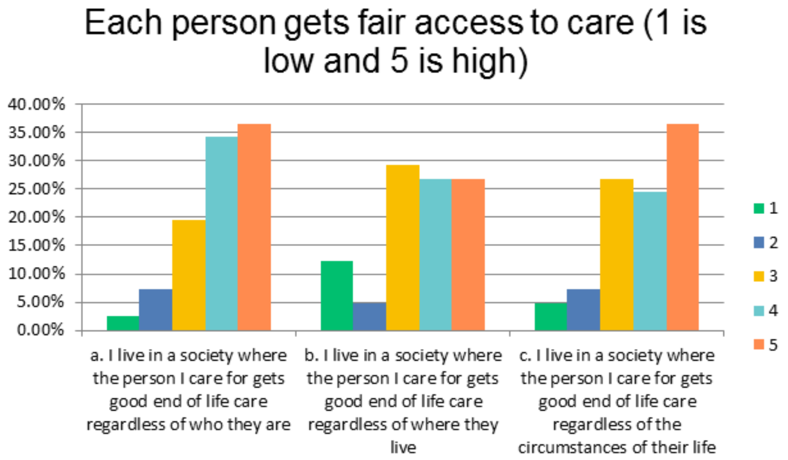
Each person gets fair access to care

Clinicians and professionals



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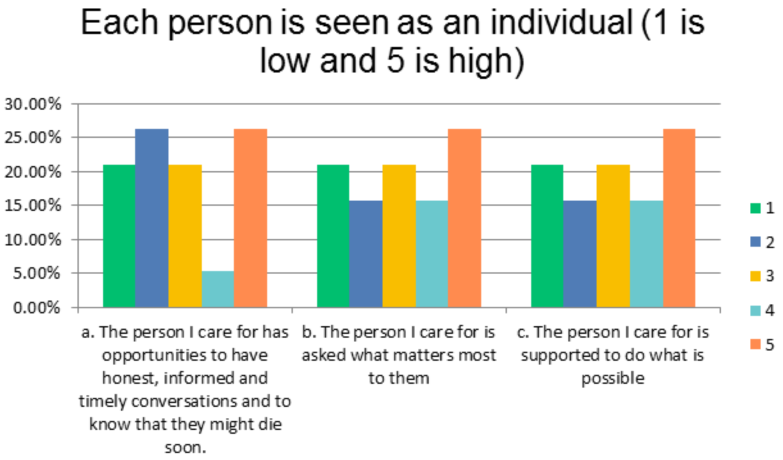
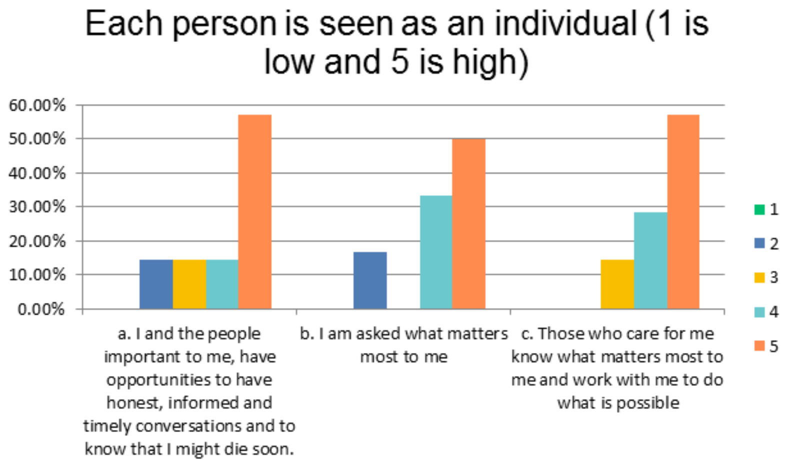


Service user



Maxamising comfort and wellbeing

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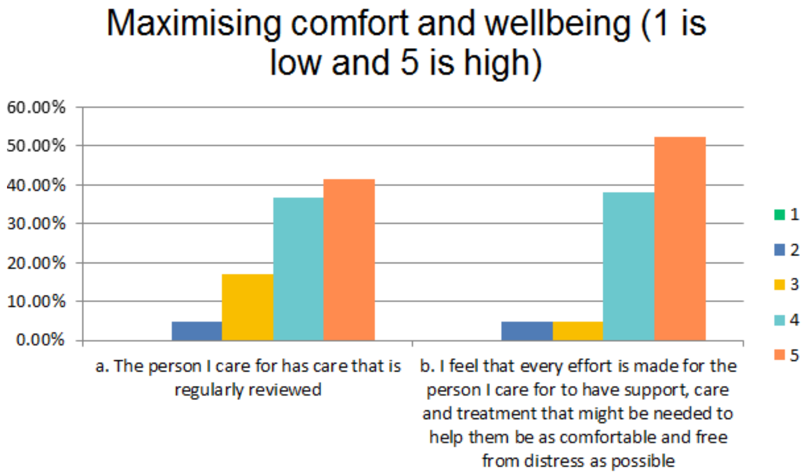
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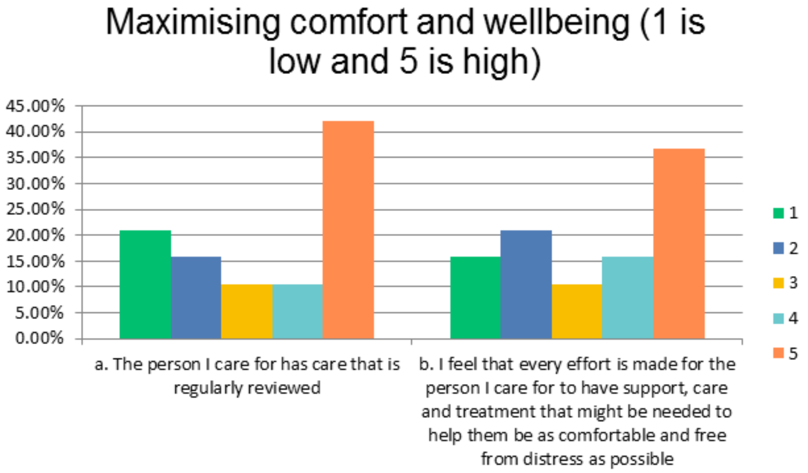
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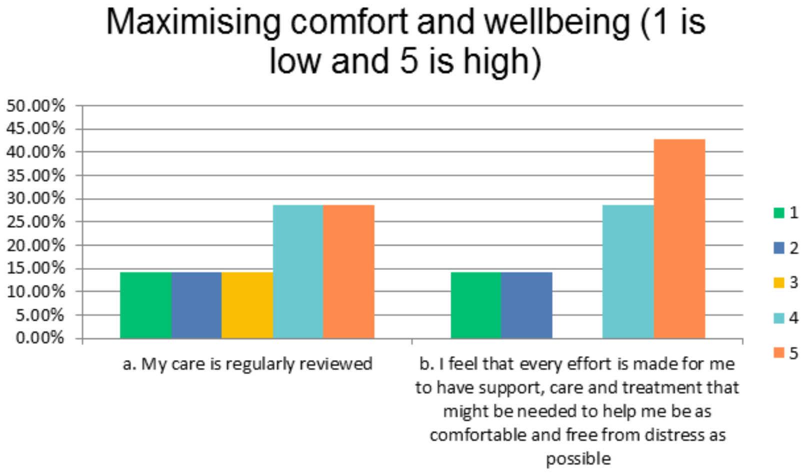
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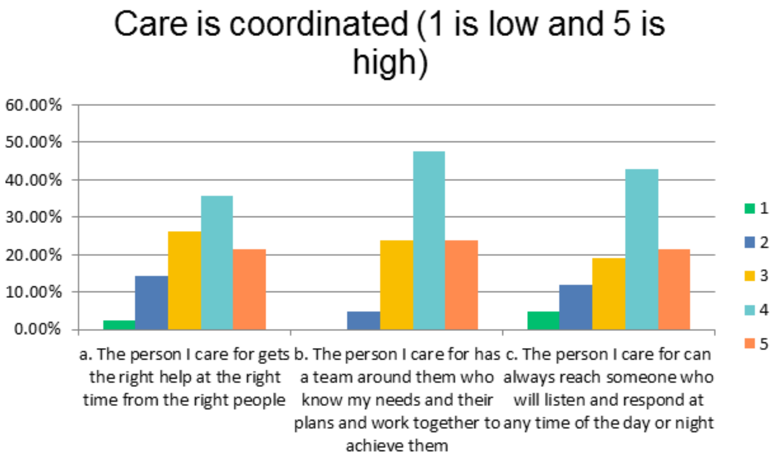
Care is coordinated

Clinicians and professionals



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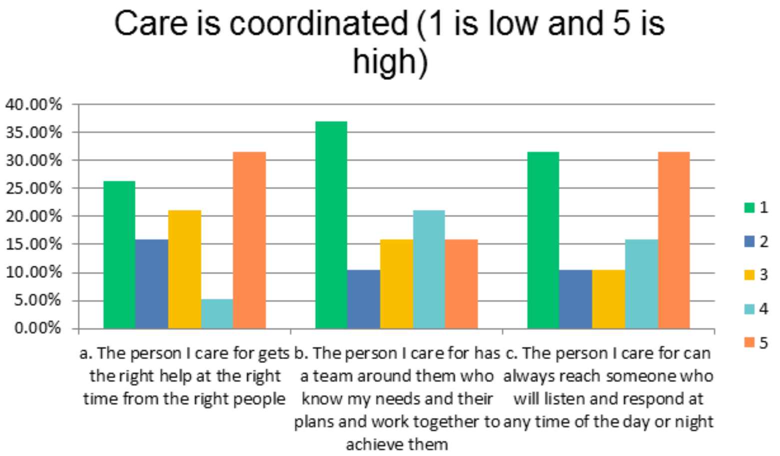

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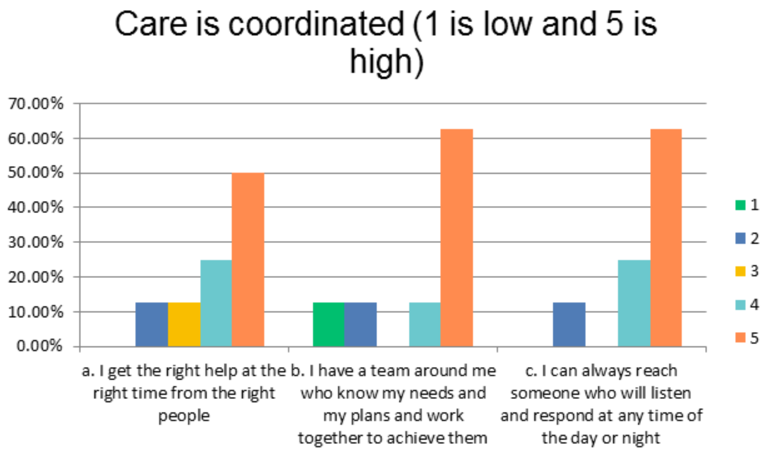
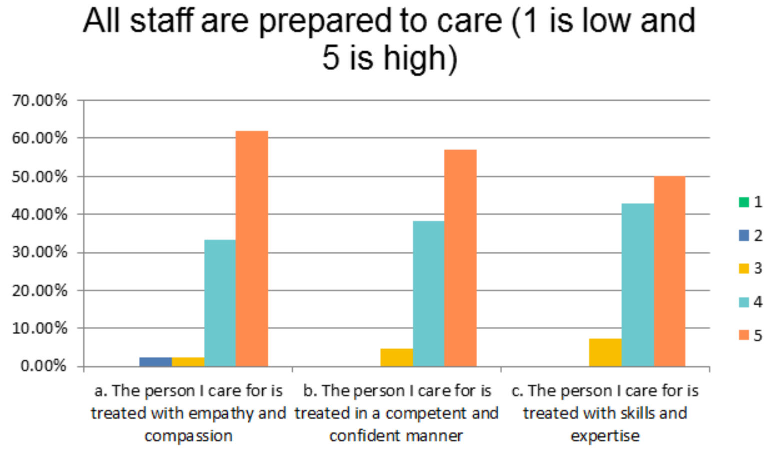


All staff are prepared to care

Clinicians and professionals



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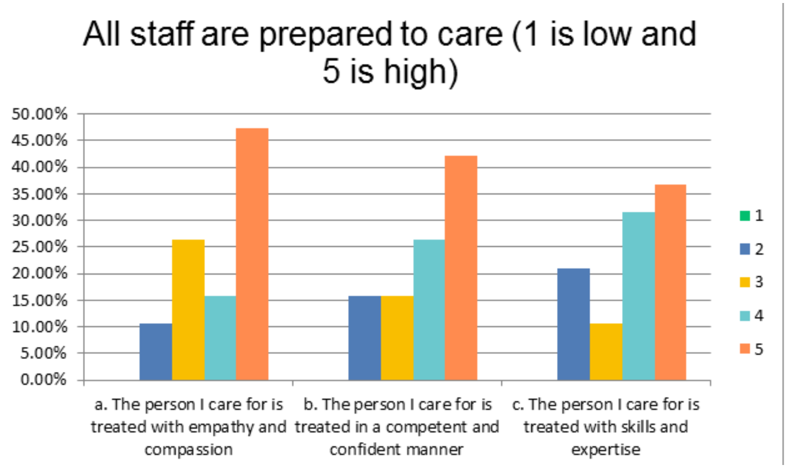

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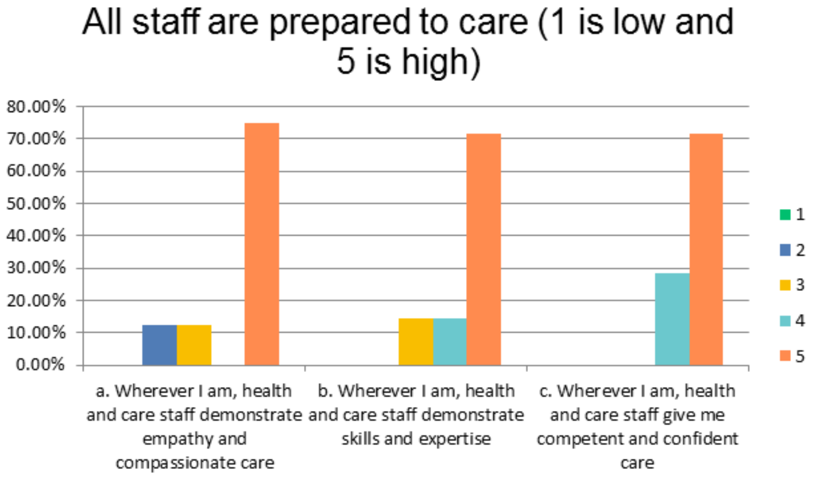
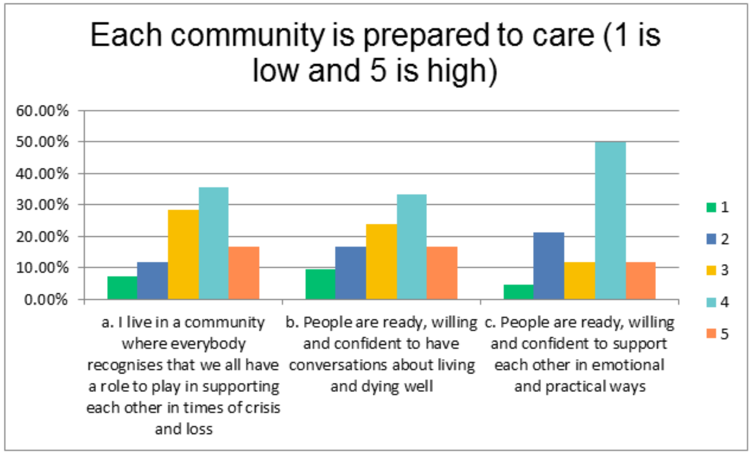


Each community is prepared to care

Clinicians and professionals



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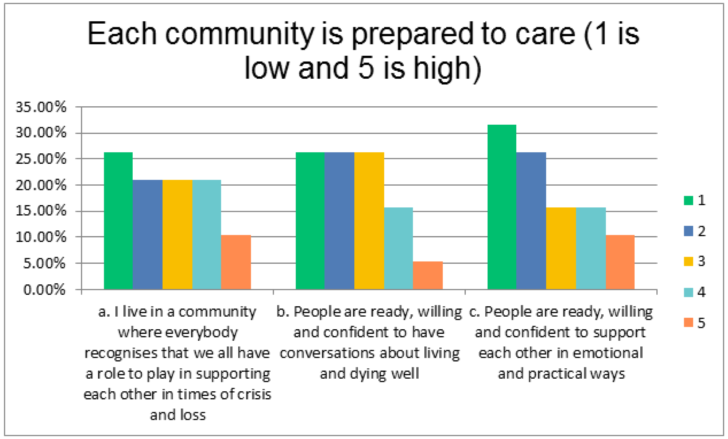

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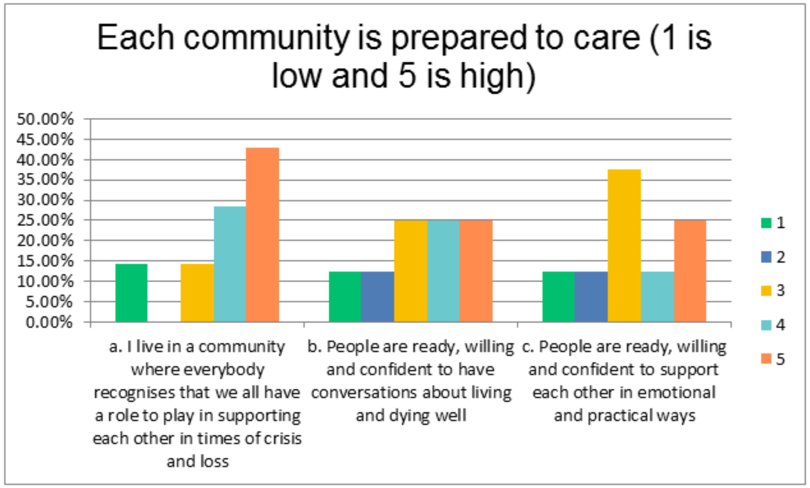

Common themes from survey

Feedback themes: survey & clinicians session

- **Availability and quality of carers**
- **Seven day working not fully supported**
- **Out of hours support** for carers and care home managers
- **Respite care:** more needed for carers - especially when there can be long waits for care packages
- **Mental Health support needed**
- **Increase capacity for community support:** Joined up health & social care approach, Death Cafes, Dead Good Festival
- **Improve communication with clinicians:** needs to be easy to understand and respectful
- **Treated as an individual**, respect and dignity

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Themes from St Leonard’s visit: 16.11.18

- The importance of having a coordinated approach to care, and having a single point of contact
- Care and compassion of staff
- Support following a bereavement
- Companionship and sharing through the drop-in sessions
- Planning of affairs
- Ensuring that advanced care planning is in place
- Excellent work of St Leonard’s hospice
- Dignity and respect
- Talking openly about dying and death
- Being given time by the staff
- Treated as an individual

Themes from public session: 22.11.18

- **Caring for the whole family**
- **24 hour access/telephone number**
  - ‘Need the confidence and support at 2am in morning when you are at home and don’t know what to do’
- **Single point of contact/coordination**
  - ‘Members of the family take on the co-ordinating role and it can be difficult with so many services’

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- **Open discussions about death and dying**
  - Increase public awareness about the topic.
  - Needs to be discussed early otherwise people are suddenly being told they have six weeks to live. Should not be called a ‘difficult’ conversation. It should be an important conversation.

Themes from public session: 22.11.18

- **Equipment**
  - Cannot wait weeks for equipment at end of life. Need to think ahead about what they need
- **Dementia and other long term conditions**
  - Cancer often has all the focus – eg money placed into MacMillan nurses, however dementia is a terminal illness and needs more support,
  - Focus of the money is too much on cancer and not enough on the other long term illnesses and life limiting conditions.
  - Massive gap at the moment in support for dementia care
- **Advanced care planning**
  - We should all be thinking about care planning. We need a ‘death plan’ just like a ‘birth plan’.
- **Language**
  - Phraseology and language are really important
  - You are very ill, does not mean the same as you are going to die

Themes from public session: 22.11.18

- **Choice of where to die**
  - It’s important that people can die in their chosen place of death
  - We should have an aspiration that we can support people to die at home if they wish
  - ‘It’s so important the timing of when people are asked about where they want to die’. Preference can change at different stages of illness – it may be at home when you are more well, and then you may want to go into a hospital or hospice towards the end of your illness.
  - People need more information about the options and the support you will get in your preferred choice for place of death.
- **Post death:**
  - Carer left at home – difficult to deal with due to memories.
  - Dying at home can have lasting and difficult memories of nursing someone
  - Bereavement support is needed
- **Seldom heard communities:** LGBT voice and Dementia care

Where next?

- Identify and address any further gaps from the feedback
- Develop a Patient Charter through engagement sessions
- Determine our local 'ambitions' for end of life care
- Draft strategy to be written by February 2018
- Action plan

CITIZEN'S CHARTER FOR END OF LIFE CARE

Supporting the people of Cheshire & Merseyside to live well before dying with peace & dignity in the place of their choice

You should expect to be supported with skilled, knowledgable, health & care professionals who can recognise that you are approaching the end of life & work together to co-ordinate & manage your care

You should expect with your agreement, that your plans, if you have made any, are shared with others involved in your care, so that your wishes may be fulfilled

You should expect that, if you wish, those who are important to you are involved in decisions about your care & treatment

You should expect a plan for care which includes food & drink, symptom control, psychological, social & spiritual support

End of life care:

- is the **total** care of a person with an advanced, progressive, incurable illness
- is not just about dying
- may last a few days, or for months or years
- begins when, and continues as long as, it is needed

You should expect to have a regularly reviewed, plan for care individual to you & your needs, which includes decisions & actions in accordance with your needs & wishes

You should expect the possibility that you may die within the next few days or hours will be recognised & communicated clearly & sensitively, to you & those who are important to you

You should expect to be supported with trained staff, who will help you to think & plan ahead, if you want to, so as to be able to discuss your wishes & preferences for your care

You should expect to be helped to remain as independent as possible & supported with health & care staff who maintain your dignity & sense of control throughout the course of your illness

You should expect the needs of your family & others identified as important to you to be respected & met, as far as possible

You should expect that you, & those important to you, will be treated with compassion & respect towards the end of life

You should expect that your body will be treated with dignity & respect after your death

You should expect that during your illness & after your death, those important to you, receive practical, emotional & spiritual support

CHESHIRE & MERSEYSIDE PALLIATIVE & END OF LIFE NETWORK

NHS Cheshire & Merseyside Strategic Clinical Networks

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Vale of York
Clinical Commissioning Group