



Northumberland
Clinical Commissioning Group

End of Life Strategy Development 2020/21



Task

Following on from engagement on the Walton Unit,

- Recommendation from OSC to review current End of Life strategy and update as required
- To ensure strategy reflects the health and social care system including voluntary/community groups
- The need to engage further with local population including hard to reach groups
- Strategy will encompass care in hospital, out in the community and within peoples homes



Developments

- Strategic task and finish group formed with key stakeholders from health and care sector including patient representative and members of OSC
- Met from January to March 2020
- Started to form local ambitions and a roadmap to achieve
- Reviewed national policy and direction with a view to ensuring integration of services
- Meetings have been delayed due to planning and action for the COVID19 pandemic



Approach

- Data: What is it telling us?
 - Working with Public Health, Primary and Secondary care Information Teams
 - How could we use data better
 - What would success look like?
- Map current pathways and highlight any gaps
- Engage with the community
- Draft strategy document



Task and Finish Group - Initial findings

- How the National Council for End of Life Ambitions could be used to map services and identify gaps
- Importance of engagement with our communities to understand and act on their views
- Social responsibilities around discussing and planning for End of Life
- Considering differences between urban and rural areas and deprivation considered through the data
- Importance of dying in a private room when in hospital

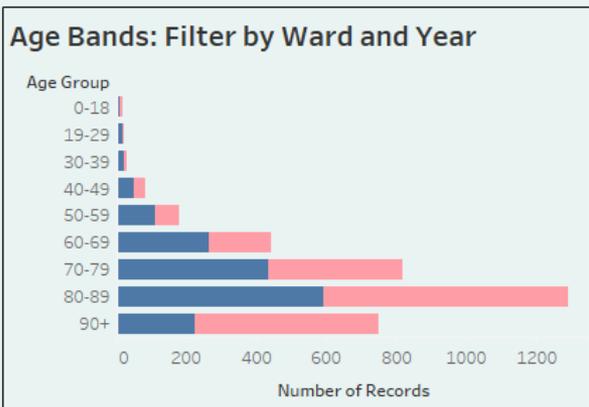
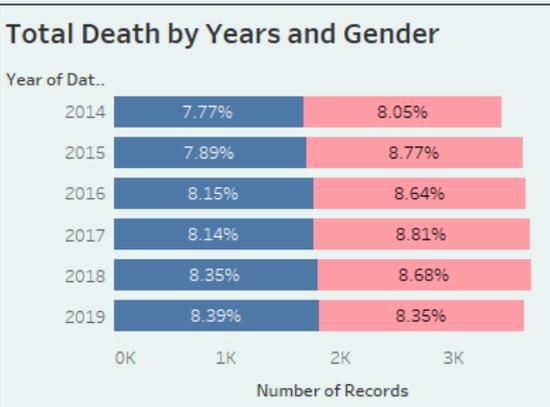
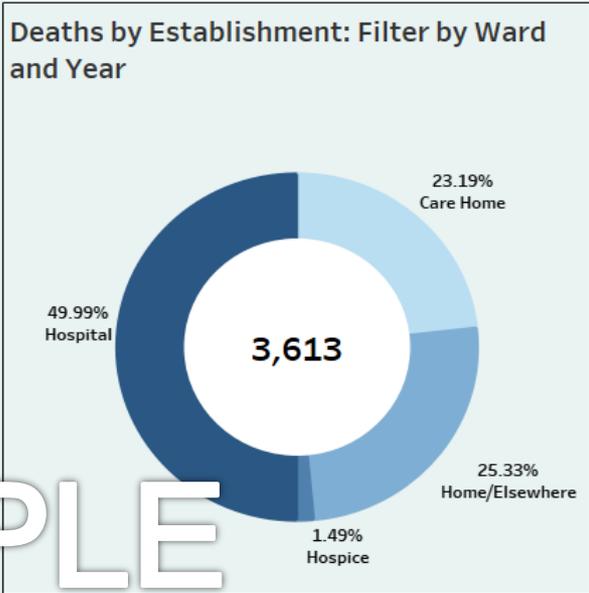
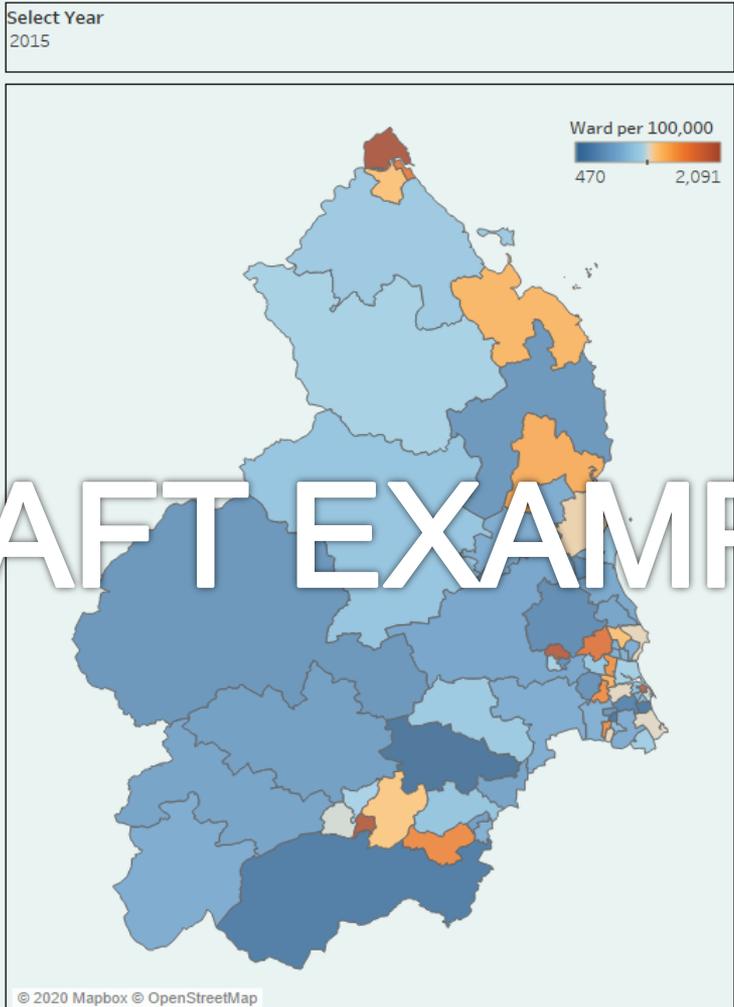
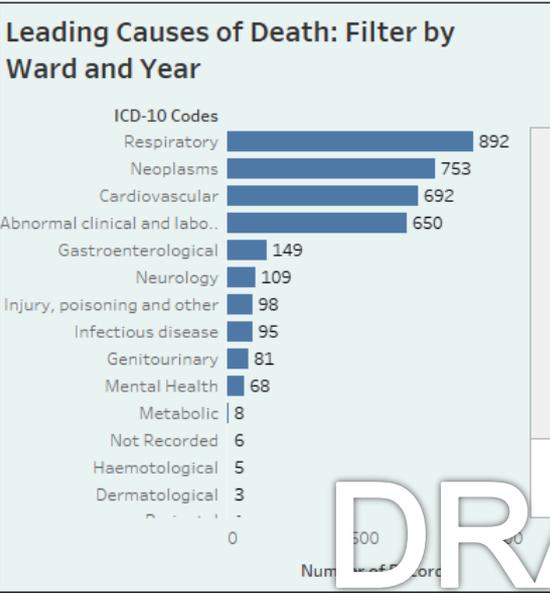


Current Progress: Data

- Data dashboard development supported by Northumbria Health FT and Public Health have supported development
- Interactive using software called 'Tableau' to allow drill down into available data sources
- Data items include:
 - Causes of death
 - Demographics
 - Place of death
 - Graphical mapping / ward level representations
 - Year on year comparison
 - Mortality rates



Data Dashboard - Screenshot



DRAFT EXAMPLE

Data Dashboard - Screenshot

Select IMD Decile

All

Select Year

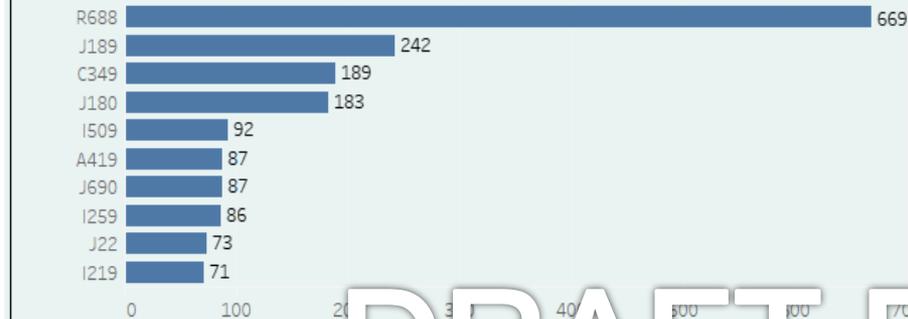
2019

To search for ICD-10 Codes please click the link to the right

<https://www.icd10data.com/>

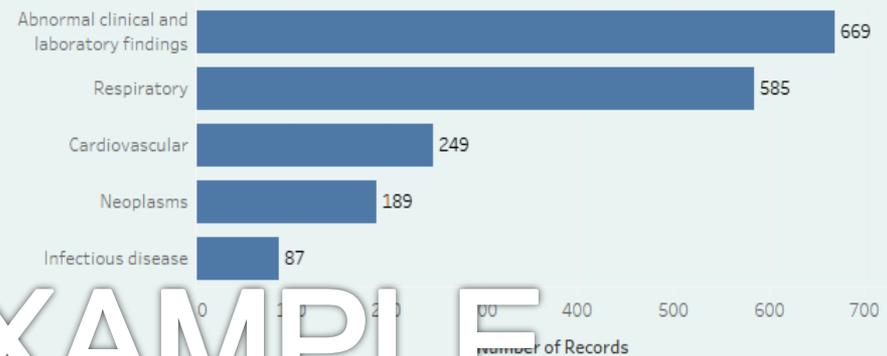
Top 10 ICD Codes

Cause Of De..



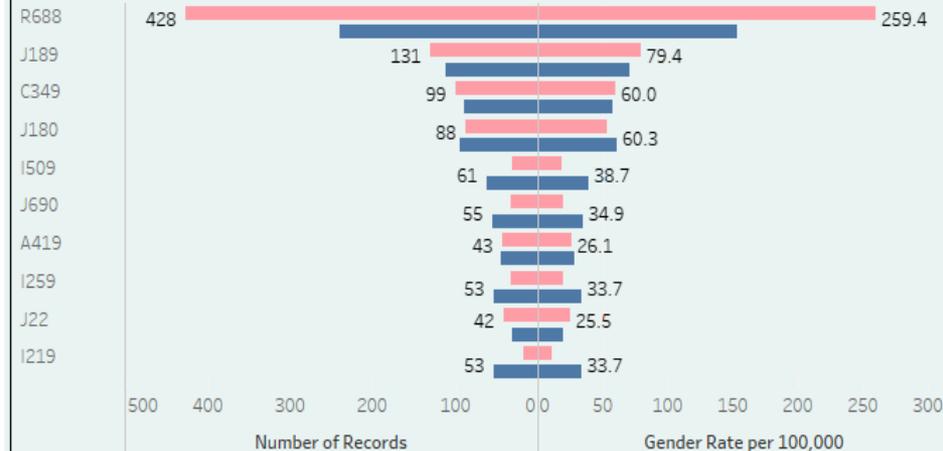
Top ICD Codes by Category (Based on top 10 ICD codes)

ICD-10 Codes



Top 10 ICD Codes Split by Gender

Cause Of De..



Top ICD Category Split by Gender (Based on top 10 ICD codes)

ICD-10 Codes



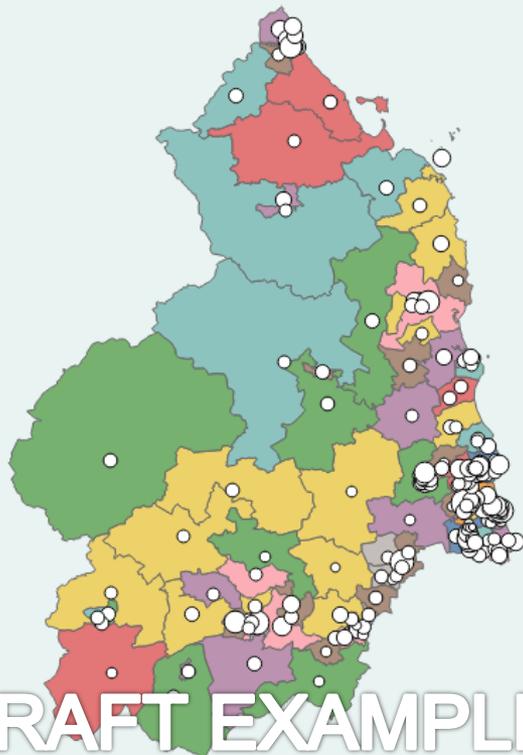
DRAFT EXAMPLE

Data Dashboard – Screenshot

Total Residents by IMD Decile (Key for Map Below)

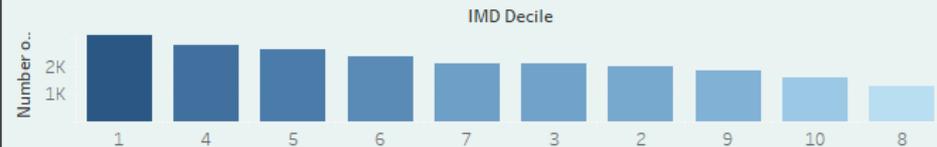
1	2	3	4	5	6	7	8	9	10
38,327	27,243	28,024	38,472	35,256	38,231	30,799	19,267	34,033	30,622

Rate per 100,000 Number of Deaths by IMD Decile + LSOA

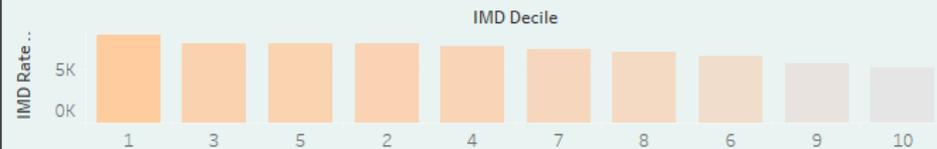


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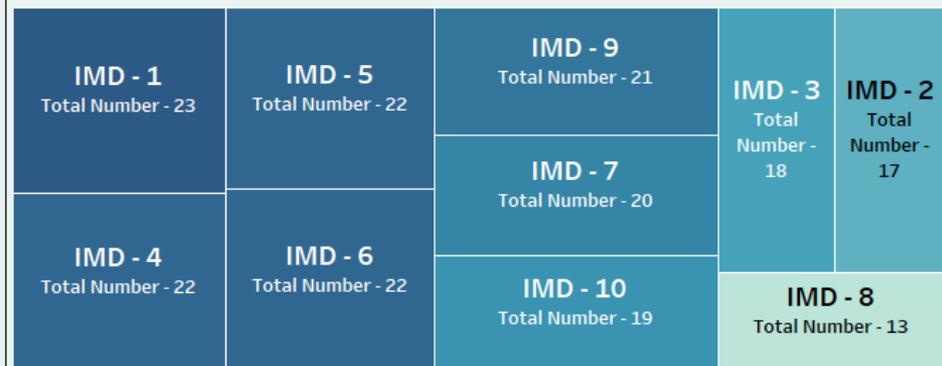
Number of Deaths by IMD Decile: Use as Filter



IMD Rate



Total Number of LSOAs by IMD Decile



Service Mapping

Based on the National Council for End of Life ambitions



Service Mapping: “Building Blocks”

- For each of the 6 National Council ambitions, providers have been asked to identify current services and gaps
- Example:

Ambition 1: Each person is seen as an individual
Building blocks to achieve this ambition

Effective systems are in place to reach patients who are approaching end of life

Patients to be given information, support and advice so they can make decisions regarding palliative and end of life care

Rapid access to needs based social and health care

Good end of life care includes bereavement



Engagement

- Review of previous engagement to inform future plans: Good Death Charter 2010 (North East), Every Moment Counts 2015 (National), End of Life Care 2018 (IPPR)
- Help to tell us: What people want? What staff should do? What organisations need to do? What communities can do?
- Principles for involving communities: How? Who?
- A different approach? Social Contract



Social Contract?

How we deliver – Asset Based



Asset based thinking



Strengths based
 What can I do, what can you do?
 We're all in this together
 People have the answers
 People can control their lives and make decisions
 How can we create community spirit?

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The Deal

Our part

- Keep your Council Tax as one of the lowest
- Help communities to support each other
- Cut red tape and provide value for money
- Build services around you and your family
- Create opportunities for young people
- Support the local economy to grow
- Listen, be open, honest and friendly
- Believe in our borough

Signed *David Molynsat*
Councillor David Molynsat, Leader of Wigan Council

Your part

- Recycle more, recycle right
- Get involved in your community
- Get online
- Be healthy and be active
- Help protect children and the vulnerable
- Support your local businesses
- Have your say and tell us if we get it wrong
- Believe in our borough

Signed

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The Deal principles

Different conversations

An asset-based approach

Know your community

Staff attitude and behaviours

Place based teams

Permission to innovate

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Social contracts



A 'social contract' is an agreement to all work together to make things better.

For example, during Covid-19 there has been a 'social contract' between the public and the government - people have stayed at home to help the NHS and protect lives and the government has helped people financially.

Do you think 'social contracts' should be used:



+3 others commented

- For this piece of content, members were introduced to the idea of a 'social contract' and were asked whether they thought such contracts should be used more or less. Overall, 67% felt that 'social contracts' should be used more.

"Collective participation drives collective responsibility and accountability. We all often complain about things being forced upon us so let's try and have things happen because they are the right thing"

"I think that the recent "social contract" regarding COVID-19 has been well observed due to the high levels of publicity and the fact that there's been a very specific, measurable aim. I'm not sure there would be the buy in for some other social contracts"

End of life care – social contracts

- For this piece of content, members were asked whether they thought a 'social contract' was needed for end of life care. Overall, 74% answered yes.



End of life care – social contracts

1 week ago Services

Research carried out in the North East showed that people wanted, where possible, a death that was free of pain, dignified, in the place of their choosing, and with family and friends nearby.

To make this happen, patients had to be open about death and their preferences, and discuss these with family or friends, therefore helping the NHS to meet their vision of a 'good death'.

Do you think we need a 'social contract' for end of life care?

Yes 74.1% (20 votes)

No 0.0% (0 votes)

Unsure 25.9% (7 votes)



commented

4

“Can a social contract survive disruptive times? Does it not require stability and assurances of ‘norms’? It also requires trust that fairness will be tantamount. The inequality between health and social care, especially in a crisis, undermines this notion for end of life care”

“It depends on the extent of the ‘social contract’ - as long as it’s not like the DNR tags that were put on at risk people at the beginning of the pandemic, often without discussion with the relevant people.”

End of life care

- The 'good death' leaflet was shared with community members who were asked to provide feedback on the charter.



The council, NHS and local people want to improve end of life care for everybody. Research was carried out in the North East and a charter for end of life care was developed. Please click on the attachment to read the charter and let us know what you think.



K commented



“On the whole, I think this is a very good, positive, document. However, what worries me is a push for people to choose to die at home. If they do, and they still do towards the end of their life, that must be supported, IF their family can cope. I would stress a real need for hospice beds, end-of-life beds, to be readily and easily available for those who decide they would rather take the strain off the family, and die in a more medical setting. We must be given the choice of both, and continuing opportunities to change our minds as death approaches.”



Principles of a 'good death'

 **Principles of a 'good death'**
3 weeks ago Services

- To see death acknowledged as part of life
- To be treated with dignity, respect and privacy, according to our wishes
- To value each individual and the contribution we may still wish to make to our family, job or social network, in a caring and supportive way
- To have clear, honest and tailored information and good communication throughout illness or frailty
- If appropriate, to be told clearly and compassionately the reality that death is coming
- To be provided, where possible with a sense of how long illness may last and information about what can be expected, to allow time to plan
- To be given the opportunity to make a plan for our care in advance, which takes account of our wishes and to have that respected by health, social care and all other services
- To have access to end of life care in the location we choose, with every effort made to support this
- To have a named key worker who will organise and coordinate care, including where this cuts across organisational boundaries
- To have clear information about whom to contact around the clock and seven days a week if advice or care is needed at home
- To be given every opportunity to take part in decisions which affect care. If the person who is dying is unable to do this then the views of people close to them must be taken into account
- To receive speedy, practical help for the end of life
- To receive the best care and support with any social difficulties
- To have help to control physical pain and to alleviate emotional distress, if they occur
- To have support with the practicalities of dying, death and matters after death
- To receive appropriate emotional or spiritual support, with our beliefs and values honoured
- To have access to appropriate specialist support, including counselling if required, for families, partners, carers and staff. This may be before or after death occurs

The key principles of a 'good death' outlined within the charter can be seen in the image above, this is also available [here](#) in a larger format.

These principles were developed based on research carried out in 2010. We want to make sure that they still include what matters to patients most when they approach the end of their life.

Do you think they include the key aspects that matter to patients when approaching the end of their life?

Yes	77.8% (7 votes)
No (please let us know what you think is missing)	11.1% (1 votes)
Unsure	11.1% (1 votes)

 commented 1

- Following on from the previous month's content, members were asked to vote on a poll which asked whether they thought the principles outlined in the good death charter included all of the key aspects that matter to patients when approaching the end of their life.
- Overall, 78% felt that they did include all of the key aspects that matter to patients.
- One member commented that they would like to ensure that no treatment or withdrawal of treatment is forced upon anyone and to address any concerns that relatives might have.

"Not to have any particular end of life treatment or withdrawal of treatment forced upon one. Also, to address any concerns relatives might have about end of life treatment"

Conclusion

- Virtual task and finish group to be held on the 23rd of September
- Completion of the data dashboard
- Completion of engagement including development of a social contract
- Consider how the impact of COVID has changed views on death and dying
- Ambition to finalise strategy by the start of the new financial year

