Innovation ECHO Network

Session 7: Population Needs Assessment

27 July 2022

www.hospiceuk.org
Network Recording Declaration

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• This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.
<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Presenters</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:30</td>
<td>Introduction</td>
<td>Rowena Lovell, Director of Strategy and Governance, Hospice UK</td>
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<tr>
<td>10:40</td>
<td>PopNAT</td>
<td>Jonathan Graham, Managing Director, Gavurin</td>
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<tr>
<td>11:00</td>
<td>Needs assessment at Derian House Hospice</td>
<td>Lynn Grayson, Director of Clinical Services, Derian House Hospice</td>
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<tr>
<td>11:10</td>
<td>Group Discussion</td>
<td>Vanessa Spinks, Head of Governance and Compliance, Derian House Hospice</td>
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<tr>
<td>11:30</td>
<td>Close</td>
<td>Rowena Lovell, Director of Strategy and Governance, Hospice UK</td>
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### Estimates: 5 Neighbourhoods (MSOA) within Study area with the Highest % 65+ (2020)

<table>
<thead>
<tr>
<th>Area</th>
<th>Value</th>
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</thead>
<tbody>
<tr>
<td>Bridlington North &amp; Bunting</td>
<td>40.29</td>
</tr>
<tr>
<td>Bude</td>
<td>39.52</td>
</tr>
<tr>
<td>Grange-over-Sands &amp; Carness Peninsula</td>
<td>39.29</td>
</tr>
<tr>
<td>Bridlington East &amp; Flamborough</td>
<td>38.86</td>
</tr>
<tr>
<td>Cleethorpes West</td>
<td>36.76</td>
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### Estimates: 5 Neighbourhoods (MSOA) within England with the Highest % 65+ (2020)

<table>
<thead>
<tr>
<th>Area</th>
<th>Value</th>
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<tbody>
<tr>
<td>East Preston &amp; Rustington East</td>
<td>58.74</td>
</tr>
<tr>
<td>Barton on Sea</td>
<td>58.02</td>
</tr>
<tr>
<td>Sidmouth Town</td>
<td>50.07</td>
</tr>
<tr>
<td>Sutton-on-Sea</td>
<td>48.85</td>
</tr>
<tr>
<td>Penmarg &amp; Kingston Gore</td>
<td>47.9</td>
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### Projections: Number of people aged 65+

<table>
<thead>
<tr>
<th>Area</th>
<th>Total Population</th>
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<tbody>
<tr>
<td>NHS Lancashire and South Cumbria Integrated Care Board</td>
<td>60,000</td>
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<tr>
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<tr>
<td>NHS Yorkshire and North Yorkshire Integrated Care Board</td>
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### Projections: Number of people aged 75+

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### Projections: Number of people aged 85+

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**PopNAT**

Jonathan Graham & Ian Appleby

27th July 2022
PopNAT Background

- Web based population needs assessment tool, launched in 2018.
- Developed to support hospice care providers and other stakeholders to **understand local need**, identify gaps in provision, and support service design and delivery of end of life care.
- Contains **data curated** from a range of sources and enhanced to meet users needs – covering the population, health, deprivation levels, and demographic make up of an area.
- Guiding UX principle to ensure users of **all abilities** could get value from the tool, regardless of previous experience working with data.
- Data presented by a **single level of geography** for each country.  
  (E: CCGs, NI: H&SCTs, S: NHS HBs, W: Local HBs).
- Data reviewed on ongoing basis and updates released twice a year.
PopNAT 2.0 Key Aspirations

Held two ‘Ask the Experts’ focus group sessions, the outputs of which informed HospiceUK’s key objectives for PopNAT 2.0:

- Give users more control around the geography by which to view the data.
- Allow users to intuitively build study areas
- Enable users to view specific datasets at more granular levels of geography
- Improved guidance around how to interpret and use the data
- Make charts and maps more interactive
- Provide context by showing data for study area alongside wider comparisons
- Enables users to revisit a particular selection at a later date
- Enables users to export data from dashboards
End of Life in Birmingham
Deep Dive Report (2021)

Luke Heslop
Public Health Division
Birmingham City Council
Birmingham JSNA Deep Dive Programme

- Established by the Birmingham Council’s Health and Wellbeing Board in 2019.
- To research health and wellbeing inequalities.
- A rolling programme of evidence reviews (4 topics per year).
- To support the Joint Strategic Needs Assessment (JSNA).
- To establish policy recommendations for Birmingham City Council, the NHS and partners.
The Deep Dive Programme

A rolling programme of deep dive reports.

2021
- End of life
- Veterans

2022
- Learning disabilities
- Dual diagnosis

2023
- Mobility impairment
- Diabetes
- Sensory impairment
- Justice health
The Structure of a Deep Dive Report

The deep dive report structure consists of:

- Introduction
- Policy
- Data
- Epidemiology
- Services
- Lived Experience
- Opportunities for Improvement
- Recommendations
Life Expectancy by Birmingham railway stations
at birth (2016/18) Males & Females

Average male life expectancy in Birmingham is 77.7 years compared to 79.4 years for England. With only nine stops, you can shave seven years off the average life expectancy of a male citizen.

Average female life expectancy in Birmingham is 82.1 years compared to 83.2 years for England. With only four stops, you can shave five years off the average life expectancy of a female citizen.

Source: ONS Deaths: 2016/18 © Birmingham Public Health 2021

Making a positive difference every day to people’s lives
Voices of Lived Experience

Six targeted focus groups were commissioned for the End of Life Deep Dive.

- Homeless Population (n=9)
- LGBT Community (n=16)
- People with Long-term Health Conditions (n=23)
- Residents of Heartlands Ward (n=13)
- Working Age Adults with Physical Disabilities (n=15)
- Young People Aged 18-25yrs (n=16)
Key Findings

Three key findings themes were developed.

- Premature and avoidable deaths
- End of life services
- Carer support and bereavement services
Key Finding 1: There are too many premature and avoidable deaths.

- Taking a “whole system approach” to work across the city to co-create situations/circumstances that are more health generating without active choice, thus making it easier for citizens to make healthy choices and live as healthily as possible.

- Further exploration of the local causes of infant mortality (including pre-pregnancy circumstances and the care of pregnant women) and the development and implementation of effective interventions that are culturally acceptable.

- Action to address and reduce inequalities in different communities particularly for the modifiable factors affecting mortality.

- Continued commitment to maintain the lowest rate of suicide of any of the core cities in England and to reduce deaths by suicide in the city and over the next decade through a zero-suicide approach.
Key Finding 2: There are Opportunities for Improved End of Life Care by Local Services.

- Promotion of conversations about death and dying. Citizens should be made aware of the importance of planning their choices and wishes.
- Promote the early identification of patients with palliative care needs and the use of care coordination processes such as the Gold Standard Framework.
- Continuation of the work of the Birmingham and Solihull STP End of Life Oversight Group to implement the national framework key areas for improvement.
- Development of coordinated 24/7 access to homecare and specialist outreach services.
- Consideration to groups that are less engaged with palliative care services (i.e., the homeless population, the LGBT community and ethnic minority groups).
Key Finding 3: Death and dying impacts those left behind and there is a demand for carer support and bereavement services in the city.

- Addressing the lack of carer and bereavement support citywide and encouraging communities to provide support within different areas of the city.

- Increasing awareness of carer and bereavement support available through development of a resource for the public and professionals.

- Coordinating with adult social care to provide improved services for carers.

- Development of specific bereavement services to deal with the trauma of losing an infant.
Outcomes

- Report was presented to Birmingham City Council Health and Wellbeing Board in Dec 2021.
- The Board accepted each of the Report’s recommendations.
- Implementation will be undertaken by the Integrated Care System.
- The Report is being used to inform the Council End of Life Policy.
- The Report highlighted the experience of carers – so an additional Deep Dive into Carers in Birmingham is being planned for 2024.
Are we meeting the needs of our families? 
*evidencing need*

Lynn Grayson Director of Clinical Services

Vanessa Spinks Head of Governance and Compliance

@DerianHouse
Project Aims

- To find out what our families **need**
- To find out about what families **want**
- To identify gaps in services through our 18 CCGs
How did we do it?

- Identified a commercial independent organisation
- Gave the study gravitas and independence with families and stakeholders
- Over 100 families interviewed
- 19 Freedom of Information Requests issued
- Stakeholders from across the region took part
- Drew upon the Prevalence Study
Results - Families

Most important services:

1. Respite
2. Hydrotherapy Pool
3. Derian on Holiday
4. Emotional support
5. Wellbeing services

*No bereaved families were spoken to – this is currently taking place*
Results - Families

Almost all families would recommend Derian House

Families praise Derian House for its ability to meet the needs of families in such a way that parents trust their child will be safe; they also feel accepted, understood and well-informed in the process.

Likelihood to recommend

97%

“When you have a child with a disability people often give you pitying looks. But at Derian, all the kids are celebrated for who they are. They are all capable as far as Derian are concerned. It's a fun place to go.”

Family of female, 4 years

“They are kind, caring, a good bunch of people. We are a family. Everyone looks out for everyone else. The staff are never in a rush and they always make time for us. They know their stuff so well so I am happy leaving my son there as I know he will be well looked after.”

Family of male, 22 years

“Because they've been amazing throughout the process and made it easier for us to understand the diagnosis and come to terms with many things. They've talked us through issues relating to end of life care. They've been so supportive.”

Family of female, less than 1 year

Q26. How likely are you to recommend Derian House to other people if they needed similar care or support?? (all excl. D/K: 99).
Results - Stakeholders

Freedom of Information requests show that the approach to palliative care for children and young people is patchy across the region.

Very few have published strategies for the care of Children and Young People with life limiting conditions, however they have recognised this and are working towards developing strategies either on a CCG basis or they are working collectively with other CCGs to develop a more system wide approach.

Freedom of Information Requests stimulated conversations – not all were comfortable with being asked

Some CCGs thought they commissioned us!
Results - Stakeholders

- Identified the gaps, including:
  - Children’s palliative care nurses
  - A rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer from the ICU to home, or to a hospice
  - Transition services
  - A level 4 paediatric palliative consultant
  - Voluntary sector children’s palliative care services
  - Bereavement care before and after a child or young person has died
  - Rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer from the ICU to home, or to a hospice
  - Step down care
  - End of life care
Results – Identified those who we aren’t reaching

Who we could help...

‘A Together for Short Lives’ report details the prevalence of children and young people aged between 0–19 years who are living with a life-limiting or life-threatening condition in the North West of England.

Overall prevalence
72.5
North West of England

Prevalence by gender
Males aged 0–19 are more likely to live with a life-limiting condition than females.

Prevalence by ethnic group
Highest among those of Pakistani origin. Lowest among Chinese origin.

Prevalence by deprivation group
Prevalence is highest among those with higher rates of deprivation.

Prevalence by age
- 221.9 Age <1
- 85.7 Age 1–5
- 58.9 Age 6–10
- 57.0 Age 11–15
- 53.3 Age 16–19

Prevalence by diagnosis
Ordered highest to lowest.
1. Congenital
2. Perinatal
3. Neurology
4. Respiratory
5. Haematology
6. Oncology
7. Genitourinary
8. Metabolic
9. Gastrointestinal
10. Circulatory
11. Other

Stakeholders - engagement

- Started the conversation with “hard to reach” Commissioners
- Many waited for the outputs to develop their own strategy’s
- Enhanced and supported the work with a key Commissioner
- Helped many identify areas where they had gaps, which perhaps they hadn’t realized
- Your Commissioners need your support to help them develop their all age strategies
Strategy Development

- Strategy for the next three years been based directly on the feedback from families and stakeholders

- Stakeholders and stakeholders views and needs are now firmly embedded into the Derian House Strategy
THANK YOU!

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Tanya Colbran, Senior Research Executive
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https://www.derianhouse.co.uk/research/
Next Session:

Topic: Digital Developments

Date: 28th September 2022

Time: 10:30 – 11:30

www.hospiceuk.org
Before you go…

https://www.surveymonkey.co.uk/r/Innovation-27-07