End of Life Care
Joint Strategic Needs Assessment

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Section 1  Executive Summary

The Joint Strategic Needs Assessment describes end of life care and the key factors that influence the care an individual is likely to receive. National, regional data and local data is presented that demonstrates that hospital remains the most common place to die although this is decreasing. In Salford, hospital deaths decreased by 13% between 2006 and 2014 whilst deaths at home and care homes increased respectively by 6% and 7%.

The nationally endorsed Electronic Palliative Care Coordination System (EPaCCS) is used widely across Salford. Use within primary varies but many GP Practices are identifying increasing numbers of patients who are nearing the end of life to enable pro-active care management.

An analysis of the leading causes of death across Salford is made with comparisons between care home, hospital, hospice and home deaths.

Three recommendations are made that are likely to impact on the quality of end of life care received by residents of Salford and their families.

Section 2  Description of End of Life Care

The National Institute for Health and Care Excellence (NICE)\(^1\) uses the General Medical Council’s definition of people ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes those whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and coexisting conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Section 3  Factors that influence End of Life Care

National and local trends in end of life care have been identified from recent literature and include:

- Equity of care for all patients nearing the end of their lives
- Responding to an ageing population
- For people with cancer:
  - Marital status was the second most important factor associated with their place of death, next to type of cancer.
  - Married people were more likely to achieve a home death than those who were single, divorced or widowed
  - People with cancer who live in less deprived areas were more likely to die at home or in a hospice
  - People over 85 who died from cancer during 2006–10 were more likely to die at home or in a hospice than in earlier periods
  - Men with cancer were less likely than women to die at home or in a hospice
- The presence of a family or informal carer is a key component in achieving a home death. Effective and sustained carer support, especially during longer illnesses, is likely to increase home death rates.
- There is some evidence suggests that the time of death may influence the place of death:
  - Around 6% of all deaths occur during the holiday weeks (Christmas, New Year, Easter)
  - The place of death varied by holiday periods – it was less likely to occur in hospital over Christmas
- A 2015 review of evidence has also highlighted that:
  - Having a cancer diagnosis is the primary determinant of access to specialist palliative care
  - People with a non-cancer diagnosis receive less generalist care than people with cancer although hey receive more social care

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2 What we know now 2013. New information collated by the National End of Life Care Intelligence Network. Public Health England, 2013
3 Equity on the Provision of Palliative Care in the UK: Review of Evidence, Personal Social Services Research Unit, commissioned by Marie Curie, April 2015.
- People from Black, Asian or minority ethnic (BAME) backgrounds were less likely to consider overall care on the last three months of life to be ‘outstanding’ or ‘excellent’.
- People in more deprived areas were less likely than those in the least deprived areas to feel they had sufficient support to care for someone dying at home, and were also less likely to die at home rather than in hospital.
- People aged 85 or over receive proportionally less specialist palliative care than other groups.
Section 4  National and Greater Manchester End of Life Care profile

National

At the beginning of the 20th century it was common for people to die at home, but as the century progressed the rate of home deaths fell while the rate of hospital deaths increased. Population-based studies exploring patterns in the place of death in England between 1993 and 2010 found\(^2\):

- Hospital remains the most common place of death
- An increase in home and hospice deaths mirrors the decrease in hospital deaths in cancer since 2005
- The proportion of deaths in inpatient hospices increased slightly among people with cancer and non-cancer (0.4% and 0.3%, respectively)

National data relating to choice is available. Just over half of respondents to the National Survey of Bereaved People (VOICES-SF) felt that their relative had died in a place of their choice\(^4\). At the same time the challenge of delivering consistently good experiences and outcomes for people at the end of their lives is growing. Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035\(^5\).

The proportion of deaths in the usual place of residence (DIUPR, deaths in own home or a care home) continues to increase and correspondingly the proportion of deaths in hospital is falling. The DIUPR figure for England was 45.1% in quarter 2 2014/15, up from 40.3% in quarter 1 2010/11\(^6\).

There is geographical variation in place of death²:

- Home deaths are most likely to occur in the Midlands and East of England (21%), with 22.5% dying at home in Norfolk, Suffolk, Cambridgeshire and Essex and 21.1% in Lincolnshire, Leicestershire, Nottinghamshire and Derbyshire
- People are least likely to die at home in Sussex, Surrey and Kent (18.7%) and Bedfordshire, Hertfordshire and Northamptonshire (18.8%). These areas also record the highest percentage of hospice deaths (7.8% and 6.7% respectively)
- Cambridgeshire has the highest proportion of deaths in a person’s own home (27.2%)
- London has the widest range of values for deaths at home. Sutton and Enfield (15.9% and 16% respectively) have the lowest percentage of home deaths while the City of Westminster has the second highest percentage (24.9%) in England

NHS Improving Quality describes Electronic Palliative Care Coordination Systems (EPaCCS) as providing a shared locality record for health and social care professionals. They allow rapid access across care boundaries, to key information about an individual approaching the end of life, including their expressed preferences for care⁷. The national use of EPaCCS continues to increase. A recent survey reported that sixty-four CCGs (30%) had operational EPaCCS, 111 (53%) had started planning for their implementation and 10 (5%) stated that they had no operational system and that planning had not started. Of those who had started planning, 40 were expecting to have operational systems by January 2014 and an additional 17 by January 2015⁸.

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Greater Manchester

Deaths in usual place of residence have been benchmarked across Greater Manchester and are seen as a proxy measure to increasing choice in place of death as most people would choose to die at home. Since 2010/11 all Greater Manchester CCGs have seen a steady increase which corresponds to the increases across England as a whole, (table 1).

Table 1

<table>
<thead>
<tr>
<th>Year</th>
<th>England</th>
<th>Bolton</th>
<th>Bury</th>
<th>Cen Manc</th>
<th>HMRC</th>
<th>Nth Manc</th>
<th>Oldham</th>
<th>Salford</th>
<th>5th Manc</th>
<th>Stockport</th>
<th>T &amp; G</th>
<th>Trafford</th>
<th>Wigan</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-11</td>
<td>40.3</td>
<td>37.1</td>
<td>40.7</td>
<td>34.5</td>
<td>37.2</td>
<td>32.1</td>
<td>34.8</td>
<td>33.6</td>
<td>32.2</td>
<td>38.1</td>
<td>31.5</td>
<td>33.9</td>
<td>34.2</td>
</tr>
<tr>
<td>2011-12</td>
<td>42.4</td>
<td>38.8</td>
<td>45.9</td>
<td>36.4</td>
<td>38.4</td>
<td>34.0</td>
<td>37.6</td>
<td>39.0</td>
<td>36.5</td>
<td>38.5</td>
<td>32.2</td>
<td>34.1</td>
<td>38.3</td>
</tr>
<tr>
<td>2012-13</td>
<td>43.8</td>
<td>40.7</td>
<td>45.4</td>
<td>34.5</td>
<td>41.4</td>
<td>34.2</td>
<td>36.0</td>
<td>40.4</td>
<td>37.0</td>
<td>40.8</td>
<td>33.7</td>
<td>34.2</td>
<td>37.9</td>
</tr>
<tr>
<td>2013-14</td>
<td>44.7</td>
<td>44.0</td>
<td>45.9</td>
<td>37.6</td>
<td>46.4</td>
<td>40.8</td>
<td>40.6</td>
<td>40.4</td>
<td>39.2</td>
<td>41.9</td>
<td>35.5</td>
<td>36.6</td>
<td>40.5</td>
</tr>
</tbody>
</table>
Section 5  Salford End of Life Care profile

Table 2 demonstrates the percentage of deaths of Salford residents by place of death. There has been a continued decrease of hospital deaths since 2006, with the lowest proportion of deaths (50%) observed in 2012. Overall, hospital deaths have decreased by 13% between 2006 and 2014. During the same period of time, the proportion of deaths in private homes, and care homes has increased respectively by 6% and 7%. In the last 5 years from 2010 to 2014, hospital-NHS deaths have decreased by 16% from 1061 deaths to 911 deaths. That equates to an average reduction of 38 deaths per year over the last 5 year period. In the same period, deaths at Home and Care home have accrued by respectively 17% and 11%, which correspond to an average increase of 16 and 6 deaths per year over the last 5-year period.

Table 2

![Graph showing the percentage of deaths by place of death from 2006 to 2014. The graph indicates a decrease in hospital deaths and an increase in deaths at home and care homes.](image-url)
NICE\textsuperscript{9} state that all people whose deaths are not sudden or unexpected (approximately 75\% of all deaths) should have their end of life care needs recognised and provided for in the last year of life. In Salford this would be approximately 1,600 individuals each year. An indication of improving equity of care across Salford can be seen by the ratio of patients receiving input from the Specialist Palliative Care at Salford Royal Hospital (48\% of their involvement is with patients with malignant disease but 52\% have non-malignant disease such as chronic obstructive pulmonary disease or heart failure). Another example of improving practice is shown in table 3. This data is taken from GP systems and demonstrates Salford EPaCCS data 2012/13 with a range of 0\% to 62\% of patients added to EPaCCS prior to death. The percentage for all Salford GP Practices is 31.8\%. This indicates that some GP Practices are taking a more proactive approach to caring for this group of patients and their families and a more standardised approach is required to ensure greater equity.

\begin{table}
\centering
\begin{tabular}{c}
\hline
\textbf{Table 3} \\
\hline
\textbf{\% on EPaCCS 2012-13} \\
\hline
\end{tabular}
\end{table}

9 NICE, Guide for commissioners on end of life care for adults, December 2011
Further evidence of a pro-active approach to caring for Salford residents who are nearing the end of life is highlighted with increasing numbers of people achieving their preferred place of death. This is reliant on a skilled health and social care workforce to enable effective communication and is promoted as good practice by NICE\textsuperscript{10}. Data from EPaCCS demonstrates the number of Salford residents who achieve their preferred place of death. Data from table 4 is taken from GP systems 2013/14 and shows that by the end of the year 62.4\% of people achieved their preferred place of death. However, data from Salford Royal NHS Foundation Trust’s EPaCCS is higher than 62.4\% which reinforces the need for whole-system reporting to enable more robust and accurate data collection. This is currently being developed in line with NHS England recommendations.

Table 4

<table>
<thead>
<tr>
<th></th>
<th>01/04/2012 - 31/03/2013</th>
<th>01/07/2012 - 30/06/2013</th>
<th>01/10/2012 - 30/09/2013</th>
<th>01/01/2013 - 31/12/13</th>
<th>01/04/2013 - 31/03/2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients on EPaCCS who died</td>
<td>954</td>
<td>1096</td>
<td>1143</td>
<td>1196</td>
<td>1264</td>
</tr>
<tr>
<td>Patients on EPaCCS who died with a PPD in place</td>
<td>566</td>
<td>690</td>
<td>728</td>
<td>776</td>
<td>834</td>
</tr>
<tr>
<td>Patients on EPaCCS who died with a PPD in place and achieved PPD</td>
<td>336</td>
<td>426</td>
<td>430</td>
<td>460</td>
<td>520</td>
</tr>
<tr>
<td>% patients on EPaCCS who died with a PPD in place and achieved PPD</td>
<td>59.4%</td>
<td>61.7%</td>
<td>59.1%</td>
<td>59.3%</td>
<td>62.4%</td>
</tr>
</tbody>
</table>

\textsuperscript{10} NICE Quality Standard QS13, End of Life Care for Adults, (Quality Statement 15: Workforce – training). August 2011
Data from the Primary Care Mortality Database has been analysed to highlight the 10 main causes of death by place of death (table 5). Some clear themes emerge:

- **Deaths in Care Homes**: Dementia is the most frequent cause of death in care homes, accounting to 25.4% of all deaths from. It is followed by Stroke (11.2%).

- **Deaths in Hospice**: Lung cancer (25%) and Oesophago-gastric cancer (9.5%) are the leading causes of death in hospices.

- **Deaths in Hospital**: Leading causes of deaths in hospitals are more or less across a variety of conditions, of which the 5 main causes are respectively
  - Stroke (10.7%)
  - Influenza & Pneumonia (10.3%)
  - Ischaemic heart diseases other than myocardial infarction (8.6%)
  - Chronic Obstructive Pulmonary Disease, COPD (7.9%)
  - Acute myocardial infarction (7.3%)

- **Home deaths**: 4 leading causes of death
  - Ischaemic heart diseases other than myocardial infarction (15.3%)
  - Lung cancer (12.4%)
  - Acute myocardial infarction (9.3%)
  - COPD (7.8%)
Table 5

Older People’s Integrated Care Programme in Salford
10 main causes of death as a proportion of all deaths by place of death
People aged 65+
Data period: 2008-2014
Data source: Primary Care Mortality Database (PCMD)

<table>
<thead>
<tr>
<th>% of death</th>
<th>Care homes</th>
<th>Hospice – non-NHS</th>
<th>Hospitals’* (Acute, community, not psychiatric)</th>
<th>Other communal establishment includes psychiatric places</th>
<th>Home</th>
<th>Elsewhere</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ischaemic heart diseases other than myocardial infarction</td>
<td>5.2%</td>
<td>1.6%</td>
<td>8.6%</td>
<td>9.3%</td>
<td>15.3%</td>
<td>15.9%</td>
</tr>
<tr>
<td>Stroke</td>
<td>11.2%</td>
<td>0.5%</td>
<td>10.7%</td>
<td>12.1%</td>
<td>3.1%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>4.8%</td>
<td>25.0%</td>
<td>5.4%</td>
<td>4.7%</td>
<td>12.4%</td>
<td>16.5%</td>
</tr>
<tr>
<td>Influenza and pneumonia</td>
<td>4.8%</td>
<td>0.2%</td>
<td>10.3%</td>
<td>9.3%</td>
<td>3.3%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Dementia</td>
<td>25.4%</td>
<td>0.2%</td>
<td>3.6%</td>
<td>12.1%</td>
<td>1.5%</td>
<td>0.0%</td>
</tr>
<tr>
<td>COPD</td>
<td>2.3%</td>
<td>2.9%</td>
<td>7.9%</td>
<td>3.7%</td>
<td>7.8%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Acute myocardial infarction</td>
<td>1.9%</td>
<td>0.1%</td>
<td>7.3%</td>
<td>2.8%</td>
<td>9.3%</td>
<td>11.6%</td>
</tr>
<tr>
<td>Other heart diseases</td>
<td>2.6%</td>
<td>1.1%</td>
<td>5.2%</td>
<td>1.9%</td>
<td>2.8%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Oesophagus-gastric cancer</td>
<td>1.3%</td>
<td>9.5%</td>
<td>1.5%</td>
<td>1.9%</td>
<td>3.3%</td>
<td>3.7%</td>
</tr>
<tr>
<td>Senility</td>
<td>9.1%</td>
<td>0.0%</td>
<td>0.5%</td>
<td>8.4%</td>
<td>1.9%</td>
<td>1.2%</td>
</tr>
</tbody>
</table>
Section 6 Conclusions

- There are numerous factors that influence where an individual is likely to die as well as their likelihood to receive specialist care. Many of these factors are likely to affect Salford residents, particularly:
  - Deprivation, as people in deprived areas are less likely to feel that they had sufficient support to care for someone dying at home and are less likely to die at home rather than in hospital
  - People with a non-cancer diagnosis receive less generalist care than people with cancer although they receive more social care.

- Nationally, hospital remains the most common place to die although this has been decreasing since 2005. Most people would prefer to die at home and the proportion of deaths at home/care home (usual place of residence) has been increasing nationally, across Greater Manchester as well as Salford.

- In 2014, 30% of CCGs had an Electronic Palliative Care Coordination System (EPaCCS) in place, this includes Salford. EPaCCS functions across primary, hospital and hospice and is developing within social care and North West Ambulance. GP Practices across Salford vary in the percentage of patients added to EPaCCS although some very good practice is clearly emerging. EPaCCS is also able to capture the patient’s wishes for place of death and recent data indicates that 62.4% of patients who made a preference had their choice met.

- Themes are highlighted that relate to the leading causes of death and place of death across Salford. Dementia is the most frequent cause of death in care home, whilst in hospice it is lung cancer. Leading causes of deaths in hospital are more or less across a variety of conditions whereas in home deaths they are more likely to be heart disease, lung cancer and COPD.
Section 7  Recommendations

1. Commissioners and Palliative Care providers from health and social care should report on lessons learned from other Greater Manchester CCG’s who have a higher rate than Salford for deaths in usual place of residence. This would need to be presented to the Long Term Conditions Commissioning Group within the next 12 months.

2. Years 2 – 5 (2016/17 - 2019/20) of the Long Term Conditions Local Enhanced Service for primary care should focus on solutions to support GP Practices to maximise the use of EPaCCS as a tool for sharing patient care and choices at the end of life. This should be underpinned by relevant education and training.

3. Whole- system reporting of EPaCCS is required as soon as possible to replace the 3 system approach that is currently in operation (GP systems, SRFT electronic patient record and CareFirst). The Long Term Conditions Commissioning Group recommends that the IM&T Board should support the prioritisation of this work to reach the whole-system deadline set by NHS England (July 2015).