Telstra Health UK End of life care analysis

1. Executive summary

ost people receive some form of care at the end of their life. This can require difficult choices between care options, having to balance the possibility of marginal benefit of treatment against the impact this may have on the quality of life for the patient and family caregivers.

The last few months of life can often involve multiple hospital admissions, extended stays, and numerous consultations and referrals. This activity can be very significant in terms of its cost, with it being estimated to account for as much as 10–12% of total health costs. Multiple interactions with different care providers can also lead to fragmented care and poorer outcomes for patients.

In 2008, the Department of Health set out a clear strategy for improving care at the end of life, leading to several national and local initiatives to promote better access to alternatives to hospital care at the end of life.

The move to integrated care models nationally, provides a real opportunity for reform and to deliver a more coordinated approach to end of life care. An effective system wide approach would also help to reduce existing unwarranted variation in patient outcomes and help to ensure more patient centred care, for end of life patients.

The aim of this latest analysis was to understand how patients receiving palliative care make use

of local health and social care services in the last 12 months of their lives and compare this to patient level outcomes. This could help to identify opportunities for service reconfiguration and ultimately result in improved quality, safety and efficiency of care for patients.

The analysis reveals there is limited data on patient's choice of preferred place of death and their actual place of death. This suggests that this information is not being routinely collected and recorded in the summary care data. If this information was routinely available and better shared across the wider health system, it may help to better inform each patient's end of life choices, including preferred place of death.

In London, Co-ordinate My Care (CMC) is an NHS service for end of life patients, which helps to co-ordinate their health and care. Every patient's plan including diagnosis, medical details, resuscitation status, medications and recommendations for the urgent care services to follow in an emergency are visible to all urgent care services including 111, out of hours GPs, ambulance and emergency departments. With a co-created plan, 77 per cent of patients died in the place they had requested.

This shows that sharing data in this way can result in more patients dying in the place that

they request. However, more needs to be done to expand this into all areas of care and not just urgent care. Not only will this improve end of life care there are also financial benefits. It is estimated that improved recognition of palliative care needs and services outside hospital could improve care and reduce hospital costs by £180m a year.

The analysis reveals that there are very distinct groups of end of life patients whose use of local health and social care services varies considerably in the last 12 months of their lives. They also have varied outcomes, with a large proportion of the most elderly and frail experiencing falls and fractures, and the patients with high mental health service usage having the lowest rate of dying in their preferred place of death.

Given the disparity in outcomes for patients, it is clear that there are opportunities in North West London to share data on end of life patients more systemically across the system to ensure more targeted support that will lead to better outcomes and quality of life in the last 12 months of their lives.



2. Methodology and data

n partnership with the Dr Foster Unit at Imperial College London we used the Whole Systems Integrated Care (WSIC) integrated dataset which covers the North West London (NWL) region. This includes eight CCGs which, since April 2021 have merged into North West London CCG. The analysis looked at patients who were recorded with either:

• QOF palliative care registry (primary care data) or,

 Palliative care (treatment function code 315 or Z515 in any diagnosis field) is recorded in an admission to hospital (secondary care data)

The cohort was restricted to patients who died between 1st January 2016 and 31st December 2019. After carrying out cluster Cluster Analysis is a technique

analysis we identified eight different groups that were based on the patterns revealed by how the patient used the healthcare system. used to look at whether data can be grouped into categories on the basis of their similarities or differences. Grouping observations that are similar into subsets, allows for trends or patterns to emerge within the data. We used an unsupervised machine learning technique called k-means clustering. The variables for cluster analysis were firstly log-normalised and standardised to reduce the impact of outliers and give an equal weight to each variable, before Hopkins statistic was used to check cluster tendency. The dataset was then split into

10 random samples and hierarchical agglomerative clustering with Euclidian distance and Ward's method was applied to each sample to determine the optimal number of clusters. Finally, the k-means cluster algorithm was applied on the whole dataset using the optimal number of clusters from the previous step, and the final number of clusters (8) determined using the "elbow method" and the "sum of squares method".

By comparing the patient demographics and outcomes for each of these eight clusters we were able to see where opportunities might be identified for service reconfiguration.

3. Research findings

Cluster 1 – Elderly, frail with Long Term Conditions (LTCs)

In cluster one we found that patients were below average in terms of their preferred place of death. While they have the highest level of frailties, they are in line with other groups for long term conditions, however they have the highest out of hospital use and the costs associated with delivering their care are above average. They have the highest percentage of acute fall admissions and at least one fracture. This group represents the most complex, elderly patients who also appear to have the worst clinical outcomes.

Cluster 2 –

Least elderly, not in care homes

Our findings show that cluster two patients are more likely to die in their preferred place of death. They represent a younger patient profile who have fewer long term conditions. Most treatment is provided in an elective care setting and outpatients departments. They have the highest use of elective care of all the clusters. Compared to other clusters, these patients are average in terms of falls and fractures.



As the lowest health service users, cluster three consists of younger patients who have fewer LTCs. There is a relatively low average cost of supporting these patients at £4,941. A higher-than-average percentage of these patients died in their preferred place of residence, however, the data is very limited for this cluster, therefore it is likely to be unrepresentative of the group as a whole.



Patients in cluster four were found to have the most contacts with GPs and other primary care services as well as outpatients. A relatively lowcost group, they are associated with below average costs at £7,455. In this group, above average numbers died in hospital, but would have preferred to die at home. These findings raise the possibility that patients who are managed mainly in primary care settings have poorer outcomes for their preferred place of death in terms of quality of support and interventions.



Cluster five represents a complex cohort of patients with the most LTCs, frailties and high levels of obesity and smoking (including current & ex-smoker). Within this group there is slightly above average GP and hospital use. Our analysis also revealed above average falls and second highest fractures. Patients have generally poor outcomes, including highest for hospital deaths, but lowest for preferred place of death. With a high use of GP services and a high number of A&E attendances or emergency hospital admissions, there are very high costs associated with this group at £18,002. In this group there may be a lack of service provision or challenges in supporting complex patients who wish to die at home.

Cluster 6 – Mostly elderly, in care homes, with best lifestyle

Within this cluster there is a high volume of patients residing in care homes. They have a better lifestyle and relatively low healthcare use except for GP care and prescriptions, and are below average for LTCs. Data shows a small number of falls and fractures and higher proportion of patients who were able to die in their preferred place of death. This could indicate better advance care planning and support for patients in care homes and add further weight to non-complex patients being more likely to be able to die at home.



Patients in cluster seven are complex elderly patients with high mental health use. They have above average falls, fractures and show as having the lowest for preferred place of death. This may suggest that mental health issues and underlying health issues are creating challenges in supporting patients in their preferred place of death.



Cluster 7 –



Patients in this cluster are mostly elderly who do not seem to be accessing GP services. However they are above average for falls and fractures. They are average for preferred place of death.

4. Summary findings

5. Recommendations

outine collection of data around preferred place of death and actual place of death

While data sets are small it is possible to infer that more complex patients, who are cared for in mainly community or primary care settings are less likely to die in their preferred place of death, whereas those in care homes are more likely to have an advanced care plan and have better support to enable their wishes to be carried out. This is consistent with previous international studies that show people living in longterm facilities such as care homes experience higher quality of care and are less likely to need transitions to other care settings, such as hospitals.

In addition, patients who are more likely to be using primary care services and outpatients, such as those in cluster four, have a greater likelihood of dying in hospital, despite indicating that their preference was to die at home.

Currently there seems to be fragmented communication between multiple providers of care for end of life patients. Repeat readmissions can be an indicator that their health is beginning to deteriorate and extra support needs to be put in place.

But Dr Katherine Buxton, palliative medicine consultant at Imperial College Healthcare NHS Trust, says that often the true number of readmissions isn't realised if a person has presented to different hospital organisations over the last 12 months; which isn't an uncommon occurrence in London. The opportunity to then pick up on a deteriorating condition and to offer advance care planning can easily be missed.

More data would be beneficial to ensure a more in-depth look into how services can be improved for

end of life patients. However the way of recording the data needs to be simplified to enable the collection of data from across the country in one place that is accessible to everyone involved in that patient's care. Currently the recording process for a patient death is different depending on the place of death. For example, GPs face a different recording process for hospital deaths than deaths in a care home. For a care home environment in North London, they may not code preferred place of death in SystmOne (the primary care clinical system), but it is recorded in CMC (Coordinate My Care). GPs may just have to infer it in the clinical record from other information recorded.

egular shared access to the data across the system, to ensure more targeted support for end of life patients.

Develop a system that enables data to be regularly and easily recorded, which can be easily accessed across all care providers. This should be used to highlight the patient's agreed treatment plan and to capture their preferred and actual place of death, to provide a measure of the care received. This will help to inform services where improvements need to be made, particularly for complex patients who need wellcoordinated care.

In North London, preferred place of death, actual place of death and advanced care plans are available in the Coordinate My Care system to assist with urgent care, but this information does not get copied across to GP systems or into WSIC.

Recording information in a simple way that is accessible to everyone would ensure better system integration and more joined-up working for everyone involved in end of life care, leading to better advanced planning, led by primary care.

Use mandatory data collection to get the conversation started By making the recording of preferred place of death part of a GP's routine, with a single place

to record the info and designated coding, can enable the conversation to be opened with the patient. It is possible that the current lack of information and recording is simply down to the fact that the GP has not had the opportunity to speak to the patient about their wishes and make an advanced care plan. Making this process a mandatory part of an appointment with an end of life patient would ensure the information is always readily available and can shape the future of their treatment, meaning the patient remains wellinformed about the progression of their illness. It can also be used to encourage engagement between geriatricians and GPs.

National data can benchmark healthcare systems to improve care and choice

Creating a national database By enabling benchmarking of

that can be accessed by everyone involved in a patient's care can provide evidence of how different healthcare systems are meeting patient choice. health systems on a national level it will help to ensure improved care and system working for end of life patients across the country.

A simplified process that enables the uploading of information into one system rather than several different ones is crucial to ensure the

information is accessible to everyone and can also help to inform services of where improvements can be made.

Proactively identifying deteriorating patients, during their last 12 months of life

Consistent use of risk stratification data would ensure that deteriorating patients can be better identified and supported, during their last 12 months of life. This would help to ensure more targeted and appropriate clinical interventions, which are designed to improve patients' quality of life, during their last 12 months of life.

6. Conclusion

Ithough there were only small data sets available for analysis, it was possible to group enough end of life patients together to see that those who relied more on primary care services and particularly those with more complex needs were least likely to find that their needs were met.

Patients in cluster five, who were mostly elderly with the most LTCs and high levels of obesity and smoking were highlighted as having slightly above average GP and hospital use. These patients had generally poor outcomes and were highest for hospital deaths and lowest for preferred place of death.

Similarly, patients in cluster four, while younger, also had a higher use of primary care services and were also lower than average for dying in their preferred place of death. This is in comparison to cluster six patients, who mainly resided in nursing homes and were the group most likely to die in their preferred place of death. As nursing home residents it is more likely they had an advanced care plan in place.

Being able to offer all end of life patients a joined-up programme of care as a matter of course, is beneficial to both the patient and the health system. Patients receive a better experience as they are able to influence how their care and treatment progresses. The health system will also benefit through better communication between teams that could reduce the need for readmission and hospital care.

The 2008 End of Life care strategy recognised that people who are approaching end of life need access to care and support 24/7 and that when community services are unable to respond to these needs, patients may be admitted to hospital as an emergency. NICE guidance recommends offering advance care planning and palliative care to people in the community who are approaching end of life, to reduce hospital admissions.

Having an elevated level of record sharing and communication between care providers does provide benefits such as more patients being able to die in their preferred place of death. The Co-ordinate My Care programme has shown that this type of information sharing works in terms of urgent care, where, with a coordinated plan, 77 per cent of patients died in the right place and 21 per cent died in hospital compared to 47 per cent at a national level. Extending this information sharing to ensure joined up working throughout the whole care journey for end of life patients will help to provide a better experience for them as well as reducing the need for costly and often unnecessary acute care.

Mandatory, simplified recording of a patients preferred place of death and actual place, which is accessible to all parties involved in their care, particularly a GP, could lay the foundations for a national strategy that can identify opportunities for improved quality, safety and efficiency of palliative care for patients.



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