HOW THE JOHNS HOPKINS ACG® SYSTEM IS DRIVING BENEFITS IN END-OF-LIFE CARE

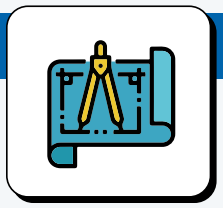
"Our ultimate goal, after all, is not a good death but a good life to the very end."

- Atul Gawande, Being Mortal

1. A Difficult Subject

In the UK we often have an uncomfortable relationship with death. Marie Curie, the UK's leading end of life charity, estimates that more than half of the population blame not knowing how to discuss death and dying as one of the main reasons for this unease. That, or we don't think it applies to us.

These factors, amongst others, are why many people find themselves in the position where they are nearing the end of their life and haven't had the opportunity, support or inclination to plan ahead.



2. Planning Ahead Makes Sense

There is no doubt that palliative and end of life care (P&EOLC) improves the quality of life of people (together with their families and caregivers) who need it. The World Health Organisation states that early identification and delivery of P&EOLC reduces unnecessary use of health services. A recent UK parliament research briefing (July 2022) further reinforces this point.

3. Model of Support - What does good look like?

A national framework for local action has been developed which sets out a vision to improve P&EOLC through integrated services across statutory and voluntary sectors at a local level. There are six key ambitions:

- Ambition 1 – Each person is seen as an individual
- Ambition 2 – Each person gets fair access to care
- Ambition 3 – Maximising comfort and well-being
- Ambition 4 – Care is co-ordinated
- Ambition 5 – All staff are prepared to care
- Ambition 6 – Each community is prepared to help

4. What Dorset Are Doing

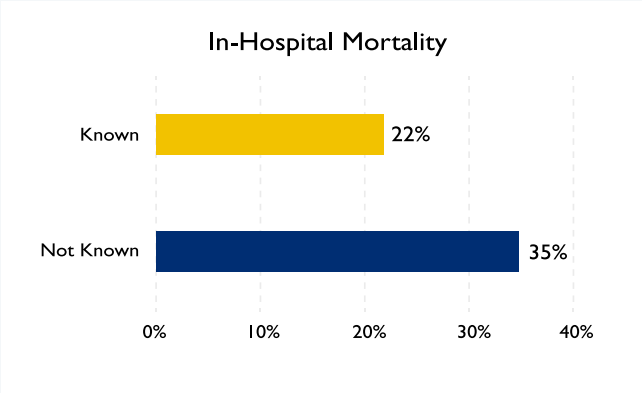
Dorset ICS are rolling out an enhanced end of life programme this year (2023) which is being delivered within the national framework. They are one of seven sites across the country participating with multiple partners working together on a model of support, "Getting to Outstanding".

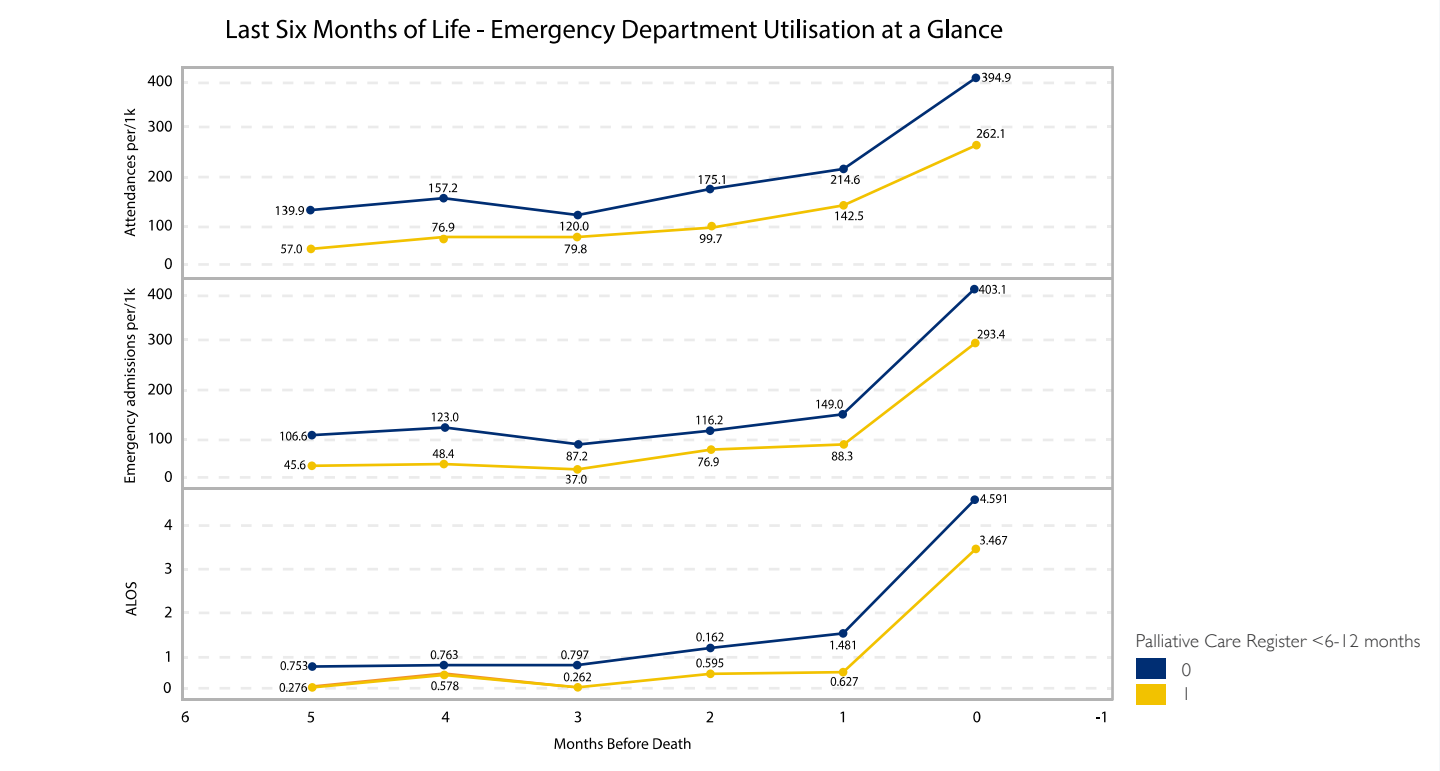
Led by Dr. Saskie Dorman, Regional Clinical Lead for End of Life, the integrated team offers a unique, personalised model that focuses on what type of care a people want to receive, whether that be a full bed bath, hands and face wash or just to chat over a cup of tea. The priority is at the end for people to be comfortable, pain free and not frightened.

5. Why They Are Doing It - A Focus on Outcomes

Janine Ord, Head of Population Health Management (PHM), has been working closely with a virtual analytical team including the Sollis Partnership, Johns Hopkins International and the Dorset Intelligence & Insight Service (DiiS), which have generated some compelling findings.

We know that in one year, approximately 8,500 people died. Of these, only 1,000 people (11.9%) were on the Supportive and Palliative Care Register. Health care professionals often describe the difficulties in identifying people proactively and this has likely resulted in a major gap across the health and care systems nationally. This gap is especially important as we know early detection results in better outcomes. Of the people who had been identified early, less died in hospital (see right). This is almost certainly because of more advanced planning.





This 'unknown cohort' of people also visited hospital more often in their last six months of life (see above). They attended the Emergency Department (ED) more frequently, were admitted into a bed more often and stayed in hospital for longer. What these system metrics don't reflect, however, is the negative experiences of people in their final months of life or the impact on their family, friends and support network.

For this cohort, the NHS needs to adopt a different approach through understanding and honouring an individual's preferences.

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6. How To Identify the Right People

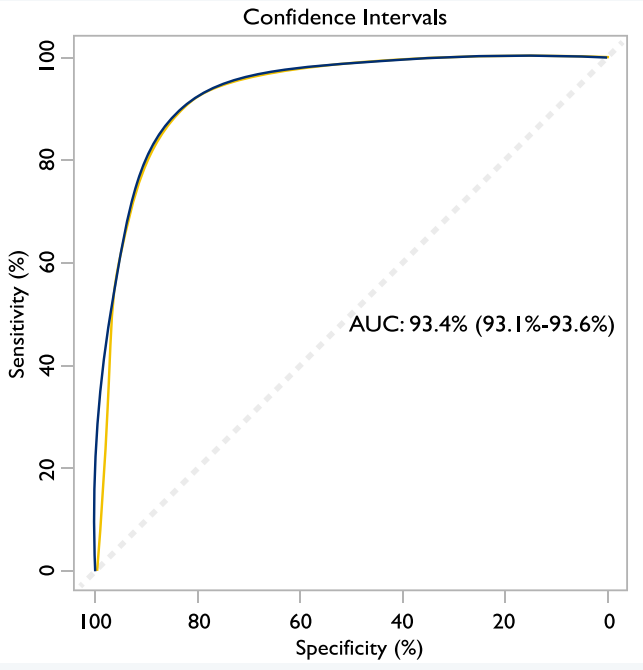
When a death can be reasonably predicted within the next 6-12 months, a person can become eligible for P&EOLC. Clinicians often ask the 'surprise question' — 'Would I be surprised if this patient were still alive in 12 months?'. This clinical judgement is critical but suffers from a limitation of scale. GPs and other practitioners can only review a small number of patients at any one time and their judgement may be prone to bias and inequity. This is where a Population Health Management approach can be successfully adopted.

7. Predictive Modeling

In 2011, a predictive model identifying people most likely to die in the next twelve months was developed in Canada[1] using the Johns Hopkins ACG System and the diagnostic clusters it generates at a person level (with a c-statistic of 0.91+[2]). These Aggregated Diagnosis Groups (ADGs) place individual diseases or conditions into a single ADG based on five clinical dimensions: duration of the condition, severity of the condition, diagnostic certainty, aetiology of the condition and specialty care involvement. A person may have none, one or a range of different ADGs as part of their clinical profile.

8. Human + Algorithm

This model has been applied to the population of Dorset, using the whole population dataset made up from primary and secondary care datasets owned by the DiiS, with every adult member 'scored' (a percentage probability). This can be an incredibly useful system-wide tool for equitably prioritising who to identify, engage and manage, but ultimately works best when it is combined with expert judgement.



We validated this model to understand how it performed, i.e. if the model indicated someone was at high risk of dying, what actually happened to them? People were scored in September 2021 and outcomes were tracked until September 2022 with some interesting results.

The first finding was that the c-statistic was superior to the original publication (see left).
Furthermore, the model was recalibrated, as sometimes models can 'drift' given changes in coding and processes. However, the recalibrated model had almost identical predictive accuracy as the original model.

1. The MRS was developed by Dr Peter Austin et al. in Ontario, Canada. The outcome of their research was a points-based scoring system that predicts risk of mortality in the adult population in the next 12-month period. The MRS combines values for a person's age, sex and the Aggregated Diagnostic Groups (ADG) information from the ACG System. More information can be found at www.ncbi.nlm.nih.gov/pubmed/21921849
2. The c-statistic is a measure of the predictive power of a binary classification model. A model with a c-statistic of 0.5 has no predictive power, while a model with a c-statistic of 1.0 is perfectly predictive.

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How could this be? Was the population and coding practices in Dorset in 2022 the same as Ontario, Canada in 2011? Possibly. However, a more likely rationale is the design, configuration and generalisability of the ACG System itself.

The Johns Hopkins ACG System is a person-level knowledge engine, or semantic layer, that is localised for whichever health system it is being implemented in and is continually managed and maintained to ensure that clinical concepts are up to date, relevant, consistent and meaningful. The predictive model remained highly performant due to the care and curation of the person-level clinical markers the ACG System generates. Furthermore, the model remains consistent in describing the 'importance' of specific risk markers (e.g. unstable chronic conditions or persistent psychosocial disorders).

9. Identifying and Supporting People

With everyone 'scored', it was important to isolate 'risk strata' or groups of people with similar risk scores. We selected the top 1% of the population with the highest risk scores for further examination.

We learned that one in four of this group did die in the next twelve months (our model's positive predictive value) and this represented 20% of all people that died that year (our model's sensitivity). This becomes particularly important when considering who to enrol in the intervention. An actionable cohort may include those who are at greatest risk of death, not currently enrolled into a model of support and who are potentially experiencing care coordination issues.

10. Expected Benefits

Risk models can only create an impact when they serve as an input into decisions as part of a funded programme of work. We are confident that the excellent work being undertaken across Dorset, together with a PHM approach to focus on those in greatest need, will drive a range of benefits including (but not limited to):

- 600+ fewer ED visits in the last six months of life (with associated costs to the commissioners of £120k)
- 500+ fewer emergency inpatient admissions (with associated costs to the commissioners of £2m)
- 5,000 potential bed days saved
- 100+ people dying in their preferred place of death

About the Johns Hopkins ACG System:

The ACG System is a flexible, transparent set of tools developed and validated by scientists and clinicians at the Johns Hopkins Bloomberg School of Public Health. Customers use the ACG System to segment their patient populations and to process their organization's existing medical, pharmacy and lab data to generate clinical risk markers and predictive models at the population and patient level. The ACG System provides health care analytics teams with the insights they need to inform rapid decisions about patient care, resource planning and service design.

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To learn more about the ACG System and how it's driving benefits in end-of-life care, please visit hopkinsacg.org, email info@jh.edu.

If you are an ACG customer, please contact your account manager.

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