

BMJ Open Development of dynamic health care delivery heatmaps for end-of-life cancer care: a cohort study

Inas S Khayal ,^{1,2} Gabriel A Brooks ,^{3,4} Amber E Barnato ^{3,5}

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ABSTRACT

Objective Measures of variation in end-of-life (EOL) care intensity across hospitals are typically summarised using unidimensional measures. These measures do not capture the full dimensionality of complex clinical care trajectories over time that are needed to inform quality improvement efforts. The objective is to develop a novel visual map of EOL care trajectories that illustrates multidimensional utilisation over time.

Setting United States' National Cancer Institute or National Comprehensive Cancer Network (NCI/NCCN)-designated hospitals.

Participants We identified Medicare claims for fee-for-service beneficiaries with poor prognosis cancers who died between April and December 2016 and received the preponderance of treatment in the last 6 months of life at an NCI/NCCN-designated hospital.

Design For each beneficiary, we transformed each Medicare claim into two elements to generate a two-dimensional individual-level heatmap. On the y-axis, each claim was classified into a categorical description of the service delivered by a healthcare resource. On the x-axis, the date for each claim was converted into the day number prior to death it occurred on. We then summed up individual-level heatmaps of patients attributed to each hospital to generate two-dimensional hospital-level heatmaps. We used four case studies to illustrate the feasibility of interpreting these heatmaps and to shed light on how they might be used to guide value-based, quality improvement initiatives.

Results We identified nine distinct EOL care delivery patterns from hospital-level heatmaps based on signal intensity and patterns for inpatient, outpatient and home-based hospice services. We illustrate that in most cases, heatmaps illustrating patterns of multidimensional healthcare utilisation over time provide more information about care trajectories and highlight more heterogeneity than current unidimensional measures.

Conclusions This study illustrates the feasibility of representing multidimensional EOL utilisation over time as a heatmap. These heatmaps may provide potentially actionable insights into hospital-level care delivery patterns, and the approach may generalise to other serious illness populations.

INTRODUCTION

Researchers have documented large, systematic variations in Medicare fee-for-service

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The development of healthcare delivery heatmaps provides detailed multidimensional end-of-life utilisation over time.
- ⇒ Healthcare delivery heatmaps are developed from the same administrative claims data used to calculate quality measures but offer increased productivity and efficiency.
- ⇒ Only cancer centres with National Cancer Institute or National Comprehensive Cancer Network designation were included in this study, therefore findings cannot be generalised to other hospitals providing cancer care.

spending and service use that are seemingly unrelated to health outcomes.¹ From a policy perspective, wide variations in end-of-life (EOL) treatment intensity across hospitals have raised concerns about inefficiencies and inequities in the Medicare programme.²⁻⁴ From a clinical perspective, they raise concerns about the quality of care delivered.⁵ To address these concerns, policy-makers and providers need more granular information to understand how and where these variations arise in order to support interventions to address these variations.

Variations in EOL treatment intensity have been described using unidimensional measures. Administrative claims data are used to calculate healthcare utilisation measures, such as total spending, hospital days or fraction of patients receiving a particular service (eg, intensive care unit (ICU) admission or hospice enrolment). In many cases, measures are not directly actionable (eg, spending, hospital days). In addition, measures often describe use of a specific healthcare service (eg, hospital care, hospice care). Consequently, these measures do not capture the full dimensionality of complex clinical care, where a multidimensional set of providers from multiple specialties provide care across many settings akin to an archipelago of disconnected healthcare islands.⁶



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Correspondence to

Dr Inas S Khayal;
inas.khayal@dartmouth.edu

Consequently, these unidimensional variables are typically described from the reference frame of a specific healthcare island, yet, improving its measures may require an upstream decision change at a prior island along the patient's journey from island to island. For example, when increasing hospice utilisation is a goal, this can only be achieved through increasing upstream referrals from non-hospice providers. Consequently, understanding a typical upstream utilisation pattern can serve as an actionable target for interventions. In other words, improving care quality becomes more actionable with a shift in reference frame from the entities comprising the healthcare system to a patient's trajectory through the healthcare system. By introducing the element of time, it becomes clearer how services are utilised relative to each other.

To date, efforts to more fully describe the longitudinal trajectory and dimensionality of complex clinical care have included combining unidimensional measures into sets of unidimensional numerical values⁷⁸ or analysing the longitudinal change of a single unidimensional measure using group-based trajectory modelling.⁹ We use systems engineering modelling to extend these approaches. Specifically, we explore the feasibility of using administrative claims to construct a map that models the dynamic utilisation of healthcare across dimensions of time, service location and service intensity or burdensomeness. These maps are developed at the patient level and describe all healthcare utilisation longitudinally in several categorisations to represent the multidimensionality of complex care. Patient-level maps are then aggregated to visualise patterns of care for cohorts of patients. Patient cohorts can be aggregated based on patient characteristics, such as clinical condition, identity measures such as gender, race, ethnicity, geographic residence or unit of the delivery system, such as a hospital or primary care practice. In the current paper, we focus on National Cancer Institute (NCI) and/or National Comprehensive Cancer Network (NCCN) cancer centres and showcase three illustrative examples to demonstrate the feasibility of this approach. Further, we seek to illustrate how depicting longitudinal and multidimensional EOL healthcare delivery utilisation as a heatmap visually conveys dynamic utilisation information that is more granular and, therefore, may be more actionable than traditional unidimensional measures.

METHODS

This section describes the methodology to develop individual-level dynamic utilisation heatmaps, then aggregate them into hospital-level dynamic utilisation heatmaps. First, we define the cohort of decedents in the Medicare claims data. Next, we describe the process whereby each decedent was assigned to the hospital where they received the preponderance of their care. We then calculated individual-level EOL care heatmaps. Finally, we sum these up to construct hospital-level heatmaps for each hospital. We showcase the dynamic utilisation heatmaps in three case examples.

Patient and public involvement

The current phase of the work is computational, with a focus on feasibility. The Data Use Agreement with the Center for Medicare and Medicaid Services does not allow us to involve patients and the public at this stage. The next stage of the work will involve patients and the public to provide input on key assumptions and to assess the usability of these heatmaps as quality improvement tools.

Data

We identified Medicare fee-for-service beneficiary healthcare utilisation using a 100% sample of 2015–2016 Centers for Medicare and Medicaid Services (CMS) files, which included 126 434 decedents with poor prognosis cancers (defined below). We included: (1) the Master Beneficiary Summary file, (2) the Medicare Provider Analysis and Review (MedPAR) file, (3) the Physician/Supplier Carrier file, (4) the Outpatient file and (5) the Hospice file. From the Master Beneficiary file, we obtained beneficiary-level information including date of death. From the MedPAR, Carrier, Outpatient and Hospice files, we obtained dates of service, hospital provider, service provided and place of service information. Furthermore, online supplemental appendix A details the fields that correspond to this information.

Cohort definition

We identified beneficiaries with poor prognosis cancers who died between 1 April 2016 and 31 December 2016 between the ages 66 and 99, had continuous inpatient and outpatient Medicare insurance in the last 6 months of life and had at least one hospital discharge or at least two clinician visits in the last 6 months of life with cancer diagnosis codes associated with a high risk of near-term death and at least one hospital admission for cancer care in the last 6 months of life. We included beneficiaries for whom we had complete 6-month look-back data coded using the International Classification of Diseases, Tenth Revision (ICD-10) codes, which began in October 2015. The look-back period was used to identify the time period for which all healthcare utilisation data would be captured and comorbidities for risk adjustment in the parent project.¹⁰ We identified patients with poor prognosis cancers to specify a decedent cohort for whom death was more likely attributable to cancer and clinicians would have been aware that time could be short.¹¹ Poor prognosis cancers were defined based on methods from Iezzoni *et al*¹⁰ that were adapted to the current ICD-10, Clinical Modification.¹² More detailed cohort development is described elsewhere.¹²

Hospital assignment

Only beneficiaries with at least one hospital admission for cancer in the last 6 months of life were attributed to a particular hospital providing the preponderance of their care for hospital measure calculations.^{10 13} We defined cancer care hospitalisations as those with a primary

diagnosis of cancer or a secondary diagnosis of poor prognosis cancer.¹⁰

We obtained hospital characteristics from the 2015–2016 Medicare Provider of Services file. We included hospitals with a focus on cancer care by identifying hospitals recognised as cancer centres by the NCI and/or NCCN, hereafter referred to as ‘NCI/NCCN cancer centres’.^{14 15} We separately analysed centres with multiple satellite affiliates as geographically unique institutions.

EOL care quality metrics

The cohort used to generate the individual and hospital heatmaps was the same cohort that was used to generate Dartmouth’s publicly available 2016 EOL cancer care quality measures¹²: (1) hospital admission in the last 30 days of life; (2) ICU admission in the last 30 days of life (National Quality Forum (NQF) #0213); and (3) non-referral to hospice (NQF #0215). The Dartmouth Atlas adjusted these measures following a modified algorithm,¹⁶ including age, sex (not race), Agency for Healthcare Research and Quality Clinical Classifications Software defined cancers of the lung, haematological and vague types;¹⁵ and Iezzoni chronic conditions.^{10 12 17} The principal investigator of the 2016 Dartmouth Atlas EOL cancer care quality report (AEB) elected not to adjust for race due to the problematic nature of attributing variation to a political construct that may reflect such complex epidemiologic risk phenomena as exposure to racism, high social needs, economic privation and environmental exposures, among others.¹⁸ The Dartmouth Atlas publicly available 2016 EOL total Medicare spending, which we downloaded for deaths occurring in 2016 by Hospital <https://data.dartmouthatlas.org/eol-chronic/#by-year>, included all chronic illness deaths (not just cancer) and was adjusted for age, sex, race, primary chronic condition, and whether patients had more than one of the nine chronic conditions.

Dynamic utilisation heatmap development

We transformed each cancer cohort beneficiary’s longitudinal healthcare utilisation into an individual dynamic utilisation heatmap. A heatmap uses colours to communicate high and low values for a two-dimensional map. Formally, a dynamic utilisation heatmap is a visual representation of a two-dimensional ‘scheduled event list’¹⁹—a mathematical construct in discrete-event simulation used to capture events and their occurrence time to simulate the behaviour of a system. Here, an event represents the use of a healthcare system capability, a construct based on a previously developed systems engineering framework for healthcare delivery systems,^{20–22} that rests on heterofunctional graph theory.²³ Briefly, a healthcare system capability represents a system’s ability to perform an activity by a healthcare system resource for a patient in the form of a subject+verb+operand to describe what action can be performed (activity) by whom or what (resource) for a patient (operand). We initially categorised activities (verbs) into the highest-level abstraction of

previously defined healthcare functions (transportation, measurement, decision and treatment).²⁰ We categorised resources (subjects) into five high-level place-based resources (home, residential facility, outpatient facility, emergency department (ED) and inpatient facility). Together, the combination of activities and resources, such as outpatient measurement, represents the set of healthcare delivery system capabilities provided to patients. We began with the highest-level capabilities.

We identified several categories with very few occurrences and others that needed to be described and highlighted in more detail. The process to identify these categories included: a data-driven approach to identify categories with few occurrences and consensus-based discussions involving input from clinicians/system scientists to review clinical relevance and frequency of categories to identify meaningful groups. The final capability categories included: (1) home health treatment at home, (2) hospice treatment at home, (3) visits at residential facilities, (4) measurement at outpatient, (5) visits at outpatient, (6) treatment at outpatient, (7) transportation to an ED, (8) measurement at ED, (9) visits at ED, (10) treatment at ED, (11) measure at inpatient, (12) visits at inpatient and (13) treatment at inpatient. Here, visits represent provider encounters to capture care decision-making. These high-level place-based resources are service locations (ie, home, residential facility, outpatient, ED and inpatient) organised with increasing values to generally relate to an increasing level of burdensomeness to the patient, as assessed by the study team and clinician consultants.

Algorithmically, we transformed administrative claims into a set of system capabilities and the times they occurred. First, we extracted the subject+verb+operand and date for each claim. Second, we identified system resources (subjects) in part A claims using facility type codes and in part B claims using place of service codes, as detailed in online supplemental appendix A. Third, we identified system functions (verbs) using Berenson-Eggers Type of Service (BETOS) codes, described further in online supplemental appendix A. Fourth, we identified beneficiaries (operands) using the beneficiary ID. We converted each claim date into the number of days from death as the occurrence time. We then combined activities and resources to calculate the system capabilities. Finally, the system capabilities and occurrence times were mapped with a value of 1 into the corresponding two-dimensional voxel in the patient-level dynamic utilisation heatmaps. In other words, the voxel value in a dynamic utilisation heatmap corresponds to the number of claims with a specific system capability (row) for a specific day before death (column). This created a patient-level heatmap. Although these individual-level heatmaps may be of interest, they cannot be shared according to CMS suppression rules because they represent a single person’s potentially identifiable healthcare use.

Once the patient-level dynamic utilisation heatmap was created for each beneficiary, we constructed hospital-level

dynamic utilisation heatmaps in three steps. First, we summed the dynamic utilisation heatmaps from all beneficiaries attributed to the same hospital. Second, we normalised each hospital-level dynamic utilisation heatmap by the number of beneficiaries included in the first summing step. Third, we checked that each heatmap voxel comprised data from at least 11 patients to comply with CMS suppression rules. Otherwise, the voxel value was filtered to 0.

Analysis

We illustrate the feasibility and potential usability of hospital-level dynamic utilisation heatmaps in four cases.

In case 1, we describe and classify hospitals based on the set of signals in the hospital-level dynamic utilisation heatmaps. First, we calculated the numerical cumulative sum for each hospital to incorporate the element of time for each system capability (row). We then classified each numerical cumulative sum into one of three quartiles: first (low), second (medium) and third (high). Finally, each hospital was classified as low, medium or high as a two-dimensional ranking for the most prominent inpatient and hospice signals.

In case 2, we compare the two-dimensional heatmap categories and unidimensional spending. We plotted unidimensional spending for each hospital and the two-dimensional heatmap categories identified in case 1. The two-dimensional heatmap categories were ordered following three steps. First, inpatient and hospice low, medium or high categories were individually assigned a

quartile value, where the value of 3 represents ‘higher’ quality and 1 represents ‘lower’ quality.⁵ For inpatient, low, medium and high corresponds to 3, 2 and 1, respectively. For hospice, low, medium and high corresponds to 1, 2 and 3, respectively. Second, the inpatient and hospice values were summed. Third, the summed values were used to order the two-dimensional heatmap categories from least to greatest. For example, high inpatient and medium hospice dimensions would lead to a calculation of 1+2 for a value of 3. In the case of ties, we ordered the poorer inpatient value first, for example, high–medium (1+2) then medium–low (2+1). Therefore, we ordered heatmap categories into high–low, high–medium, medium–low, high–high, low–low, medium–medium, medium–high, low–medium and low–high.

In case 3, we compare information from hospital-level heatmaps and two-dimensional quality measures. We plotted quality measures on a two-dimensional scatter plot and colour-coded each hospital point based on the hospital heatmap categories identified in case 1. We plotted two figures with non-referral to hospice (NQF #0215) on the x-axis and either inpatient admission in the last 30 days of life or ICU admission in the last 30 days of life (NQF #0213) on the y-axis.

In case 4, we compare the hospice at home heatmap signal and the non-referral to hospice (NQF #0215) quality measure to showcase dynamic versus static information.

All heatmap development, analyses and visualisation were completed using open-source Python 2.7.12 (<http://www.python.org/>).

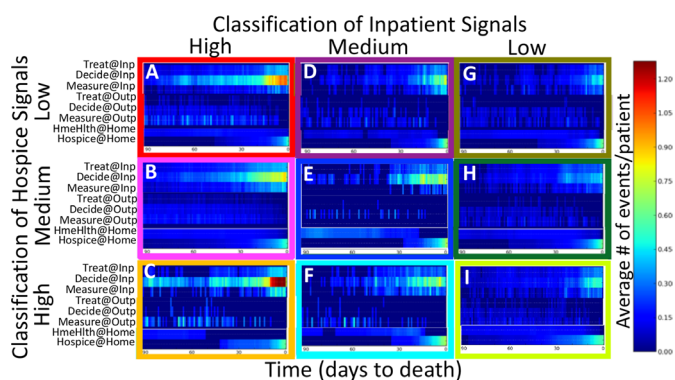


Figure 1 A representative hospital-level dynamic utilisation heatmap from a single National Cancer Institute/National Comprehensive Cancer Network hospital for each of the nine heatmap colour categories classified based on inpatient and hospice longitudinal signals. Each letter is a hospital. The colour border is the category of hospital, based on the hospital’s ‘signal’ intensity for inpatient care (columns) and hospice care (rows). The ‘heat’ of the voxel indicates the intensity of service utilisation, with blue (cool) being low intensity of use and red (hot) being high intensity of use. (A) High–low (red), (B) high–medium (magenta), and (C) high–high (orange), (G) low–low (olive), (H) low–medium (green), (I) low–high (lime), (D) medium–low (purple), (E) medium–medium (blue), (F) medium–high (cyan). The ‘measure at outpatient’ pattern is present in heatmaps (A) and (C). Note: only 8 out of the 13 rows with significant signals have been included here.

RESULTS

Beneficiary and hospital statistics

Among 126 434 Medicare decedents with poor prognosis cancers, a total of 10 119 were attributed to 54 NCI/NCCN cancer centres, with an average of 187 beneficiaries (SD 124) per centre and a range of 44–633 beneficiaries.

Case 1

Hospital-level dynamic utilisation heatmaps included 13 capabilities on the y-axis, grouped by place of service (ie, inpatient, ED, outpatient and home). For advanced cancer decedents in the last 6 months of life, we observed hospital-level heatmap signals in the measure/visit/treat at inpatient, measurement at outpatient and hospice at home capabilities. The measure+visit+treat inpatient signal cumulative sum (inpS) was used to classify each hospital inpatient signal as low ($\text{inpS} < 50.44$), medium ($50.44 < \text{inpS} < 81.30$) or high ($\text{inpS} > 81.30$). The cumulative hospice signal sum (hosS) was used to classify each hospital hospice signal as low ($\text{hosS} < 10.44$), medium ($10.44 < \text{hosS} < 16.45$) or high ($\text{hosS} > 16.45$). The combination of these groups led to nine possible inpatient-hospice combinations: low–low, medium–low, high–low, low–medium, medium–medium, high–medium, low–high, medium–high and high–high. Figure 1 shows a representative heatmap for each of the nine patterns. Given modal

Table 1 Classification of hospital-level heatmaps into nine possible groups based on three hospice at home signal groups (low, medium, high), three measure/visit/treat at inpatient signal groups (high, medium, low)

		Classification of Inpatient Signals		
		High	Medium	Low
Classification of Hospice Signals	Low	8*	1	1
	Medium	2	22*	3
	High	1*	10*	6*

*Indicates that the group includes at least one hospital with a 'measure at outpatient' signal.

population preferences for receiving EOL care at home rather than in the hospital,^{24 25} high inpatient signal intensity and low hospice signal intensity would generally correlate with worse EOL quality. In comparison, low inpatient signal and high hospice signal intensity would generally correlate with better EOL quality. **Table 1** shows the number of hospitals classified for each of the nine groups.

Table 1 also highlights the groups with the 'measure at outpatient signal'. At eight hospitals, we identified a unique high signal intensity in outpatient capability with a cumulative outpatient signal sum (outpS>61.59). The signal was strongest among three cancer centres that belonged to the same healthcare system but operated in three different and distant states (Mayo Jacksonville, Florida; Mayo Phoenix, Arizona; and Mayo Rochester,

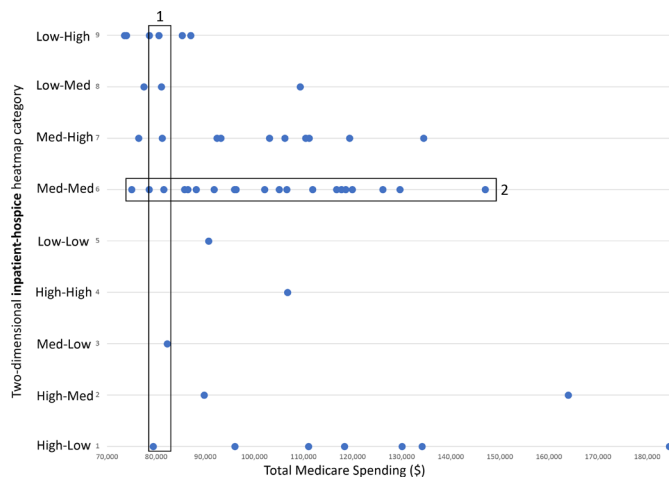


Figure 2 A plot of total Medicare spending on the x-axis, and two-dimensional heatmap categories, on the y-axis, for each of the 54 National Cancer Institute/National Comprehensive Cancer Network hospitals. Hospitals with the 'highest-quality' two-dimensional heatmap category of low inpatient and high hospice showed the lowest spending pattern (low-high). Other heatmap categories, both 'good' (eg, medium-high) and 'poor' (eg, high-low), showed a large range of total Medicare spending. This figure suggests that (1) different care delivery patterns can lead to similar spending costs and (2) similar care delivery patterns can lead to a large range of spending.

Minnesota). In addition, we identified weaker but observable signals in five other cancer centres across different states (Ronald Reagan UCLA, Los Angeles, California; H Lee Moffit Cancer Center & Research Institute, Tampa, Florida; Northwestern Memorial Hospital, Chicago, Illinois; Robert Wood Johnson University Hospital, New Brunswick, New Jersey; and St. Luke's Health Baylor, Houston Texas). The 'measure at outpatient signal' for Robert Wood Johnson University (A) and St. Luke's Health Baylor (C) are shown in **figure 1**. Examples of BETOS codes aggregating to these intense signals at these eight sites include T1H (Lab tests—other (non-Medicare fee schedule)), T1D (Lab tests—blood counts) and T1A (Lab tests—routine venipuncture (non-Medicare fee schedule)). This strong 'measure at outpatient signal' can arise if: (1) a large proportion of patients continually receive a low-to-moderate number of tests in an outpatient setting or (2) a moderate-to-low proportion of patients continually receive a large number of tests in an outpatient setting or (3) a combination of the former and the latter.

Case 2

We plotted the Dartmouth Atlas total EOL spending for each hospital versus the heatmap categorisation based on the two dimensions of inpatient and hospice signals in **figure 2**. Hospitals with the 'highest-quality' two-dimensional heatmap category (low inpatient and high hospice) showed the lowest spending pattern (low-high). Other heatmap categories, both 'good' (eg, medium-high) or 'poor' (eg, high-low), showed a large range of total Medicare spending. **Figure 2** suggests that (1) different care delivery patterns can lead to similar spending costs and (2) similar care delivery patterns can lead to very different spending costs. In other words, while measures of spending focus on how much money is spent, heatmaps provide a visual explanation of how the money is spent. Therefore, a univariate measure of spending is insufficient to understand care delivery practices and hides a significant amount of heterogeneity.

Case 3

We plotted ICU admission in the last 30 days of life (NQF #0213) and non-referral to hospice (NQF #0215), and we colour-coded each hospital based on the heatmap category described in case 1. We repeated this analysis for inpatient admission in the last 30 days of life and non-referral to hospice (NQF #0215) in **figure 3**. Neither plot showed a strong clustering of points in the same heatmap colour category. **Figure 3** shows that many hospitals with extreme quality measure values of more than two standard deviations from the mean tended to be classified into the expected most extreme heatmap categories. For example, the Robert Wood Johnson University Hospital (A) was classified in the red category with high inpatient and low hospice, as the quality measures suggest. However, **figure 3** also shows many hospitals with average quality measures that tended to fall around the mean

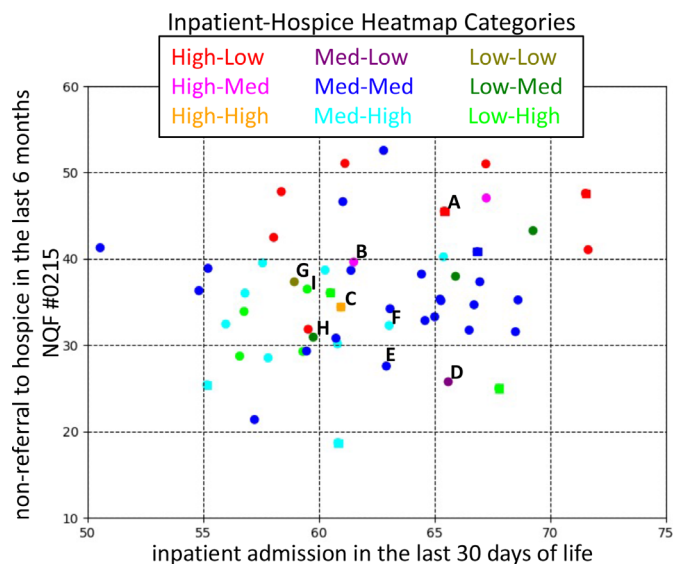


Figure 3 A scatter plot of inpatient admission in the last 30 days of life by non-referral to hospice in the last 6 months National Quality Forum (NQF) #0215, colour-coded with the nine inpatient-hospice heatmap classifications (legend). Squares represent hospitals with a high measure at outpatient signal. The letters represent the nine hospitals from figure 1. No strong clustering of points appears for the same heatmap colour category, even for hospitals within the same quadrant of univariable space (eg, B, C, G and I). The University of Alabama Hospital (I) with average unidimensional quality measures was classified into the highest quality category of low inpatient and high hospice use, highlighting much more heterogeneity within the ‘middle’ average hospitals. Thus, aggregate unidimensional quality measures hide a significant amount of heterogeneity.

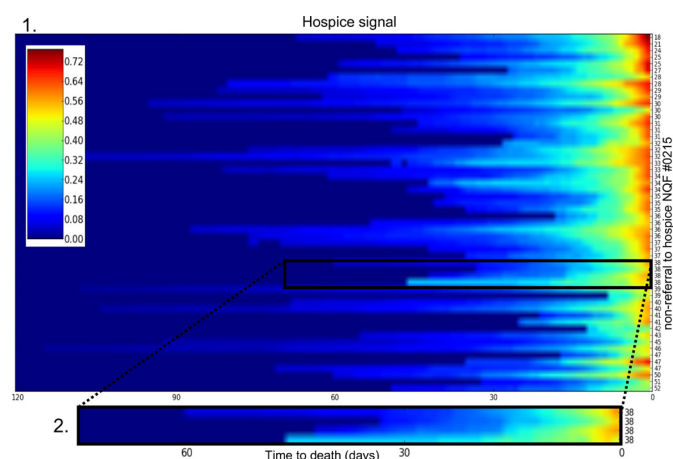


Figure 4 (1) Hospice at home signal for the 54 National Cancer Institute/National Comprehensive Cancer Network hospitals sorted by increasing values of non-referral to hospice, National Quality Forum (NQF) #0215. (2) The heatmaps for four hospitals with the same NQF value illustrate heterogeneous rates of referral to hospice over time. They visualise both the number of people and the length of time in hospice. In contrast, other metrics such as ‘mean hospice length of stay’ average the number of people and time, thus, hiding the visible heterogeneity here.

and within the same quadrant of univariable space were classified into different heatmap categories. For example, hospitals B, C, G and I appear close to each other based on their quality measures. Still, each hospital was classified into a different heatmap category. Furthermore, the University of Alabama Hospital (I), with average inpatient admissions and non-referral to hospice, was classified into the highest quality category of low inpatient and high hospice use, highlighting much more heterogeneity within the ‘middle’ average hospitals. Thus, aggregate quality measure values hide a significant amount of heterogeneity.

Case 4

In figure 4(1), we visualised the ‘hospice at home’ signal, sorted by the non-referral to hospice quality measure values (NQF #0215). The hospice at home signal for the last 4 months prior to death demonstrates the dynamic referral of patients into hospice over time. Even for centres with identical unidimensional non-referral to hospice values, heatmap colours highlight the heterogeneity in patterns leading to a similar final value at the time of death. To highlight this heterogeneity, figure 4(2) expands four hospital heatmaps with an identical 38% non-referral to hospice value (NQF #0215) for the day of death but with heterogeneous hospice heatmap signals over time. The first hospital shows very early referral starting 60 days before death with a slow increase over time and a very fast referral rate for the last 10 days. In contrast, the fourth hospital shows a later referral start but a faster, steady referral rate per day.

DISCUSSION

In this retrospective cohort of Medicare fee-for-service decedents with poor prognosis cancers who received care at NCI and/or NCCN cancer centres, we demonstrate the feasibility of developing dynamic utilisation heatmaps at the EOL that provide rich insight into patterns of systematically different EOL care for their advanced cancer patients. Furthermore, we illustrate that the same Medicare data inputs can generate more granular and potentially actionable patterns of healthcare delivery utilisation using heatmaps that ontologically model both ‘what care was provided’ and ‘by whom’.

Our approach is feasible. It relies on the same data inputs used for calculating Dartmouth Atlas and NQF-type measures.^{26–28} It can be programmed using open-source software to provide quantitatively and visually differentiated patterns. Such an approach is responsive to calls by Panzer *et al* to provide ‘room for new methods, such as pursuing analysis of big data to sift through large amounts of data in search of hidden patterns that could guide creative improvements’.²⁹ In addition, this work provides a concrete exemplar of integrating discrete event simulation and big data, described as a means of transforming healthcare delivery to be efficient and patient centred.³⁰ We argue that by including both the

longitudinal and multidimensional aspects of care, dynamic utilisation heatmaps more closely approximate a reference frame clinicians use to conceptualise patient trajectories of care.^{31–33} Therefore, it may more easily map onto how they think and make decisions about patients.

For example, Barnato *et al* developed an EOL intensity measure. They validated it as a real hospital attribute,³⁴ yet as a single value, it does not provide detailed longitudinal information for specific services performed at distinct places of service. Heatmap patterns need not rely on the decedent follow-back method, as they can also be generated based on an index diagnosis. This is because the underlying heatmap methodology generates individual-level heatmaps that align healthcare utilisation across patients using either a start or end date. Furthermore, hospital-level heatmaps are simply the sum of aligned individual-level heatmaps. Consequently, several heatmaps could be used to create informative comparative summary information by summing across patients within any patient cohort group, such as age, race, sex, diagnosis or any provider cohort group (such as physician group practice). While CMS Data Use Agreement suppression rules³⁵ prohibit sharing individual-level heatmap exemplars here, we imagine that patient-level dynamic utilisation heatmaps could allow patients to compare their own historical healthcare utilisation relative to other ‘patients like me’.^{36 37} This is feasible today through the CMS Blue Button 2.0 digital technology, which provides Medicare beneficiaries access to their data and allows third-party developers or researchers to develop applications for patients to access and view their historical healthcare utilisation.^{38–40} Future work will explore whether and how patients might use such information.

We demonstrate that we can identify meaningful differences in patterns of multidimensional healthcare delivery utilisation from these heatmaps. First, heatmaps relay potentially actionable longitudinal information otherwise averaged out when calculating quality measures and spending. For example, by capturing the full referral to hospice behaviour over time, we can observe and potentially evaluate differences between quality-improvement strategies. Earlier referral to hospice can now be distinguished from later referral to hospice; otherwise, captured as the same value using quality measures. Longitudinal information can be used to address unintended consequences of quality measurement, including the perverse incentives that lead to gaming to improve measures artificially.⁴¹ For instance, the non-referral to hospice value can be artificially improved by discharging patients from the hospital to hospice shortly before death, leading to short hospice stays (ie, 7 days or less), which limits the clinical benefit to patients and family.^{42 43} In an attempt to capture longitudinal information, a metric measuring the percent of patients who died of cancer and spent fewer than 3 days in hospice was introduced.⁴⁴ While this begins to bring in longitudinal information, heatmap images allow for the analysis of a much longer time window, especially when the effect on timing is unknown. Second, the

multidimensional information relays the overall care of a population and takes into account specific behaviours within different parts of the overall system (inpatient, outpatient, etc) For example, improving access to outpatient palliative care services can lead to changes in utilisation behaviour in both referral to hospice and inpatient or ICU use at the EOL. Taken together, the ability to visualise longitudinal and multidimensional utilisation can more easily support system-wide strategies for improving EOL cancer care. System-wide strategies are especially valuable when different parts of the healthcare organisation have large differences between quality values, which may lead to varying levels of willingness to change. Unlike previously developed longitudinal care trajectories, which can represent a single variable or a set of events in a single variable,^{9 45 46} dynamic utilisation heatmaps provide longitudinal and multidimensional information incorporating both service and resource used.

The strengths of this study include the ability to efficiently combine multidimensional and longitudinal data to describe specific signals within a hospital, for varying times relative to death, that are calculated at the patient level and can be aggregated by several patient characteristics. Nevertheless, our analysis has limitations. We restricted the analyses to include only beneficiaries with at least one inpatient admission for purposes of hospital attribution. Future analyses will include these beneficiaries by removing the hospitalisation requirement and attributing based on active treatment receipt, including home hospice, in the year prior to death. Commensurate with prior work, we attributed a beneficiary’s full EOL treatment to a single centre at which they received the preponderance of EOL inpatient services,^{12 47–49} yet patients do travel to receive care from other facilities during the last 6 months of life. Therefore, the hospital patterns may not be explicitly for those delivered by the hospital, but they represent the patterns received by the patients attributed to the hospital. As healthcare financial models continue to shift from fee-for-service towards value-based care, we expect this limitation would provide very useful information to hospitals.

Dynamic utilisation heatmaps do not serve as a prescriptive tool for change. Instead, they serve as a descriptive tool to complement on-the-ground clinical knowledge and provide guidance to explore causal relationships, referral patterns or decision-making. While dynamic utilisation heatmaps elucidate behaviours that emerge from a hospital’s population, these behaviours should not be attributed only to the providers or hospital system. Indeed, healthcare utilisation in claims simply indicates the decision to use service and provides no direct information about the level of shared decision-making between providers and patients and their families or individual-level preferences. Therefore, when reflecting on behaviours that emerge from these heatmaps, it is essential to question or ascertain decision choices by both the providers/hospital system and patients and their families. The field of industrial engineering and operations research uses heatmaps

and simulations to inform decision-making at the level of individual hospital processes.^{50–56} This paper demonstrates the feasibility of extending these approaches by using administrative claims. Future work will be needed to explore the usability and acceptability of these heatmaps by decision makers and to assess the validity of our study team's valuations of the relative burdensomeness (ie, location on the y-axis) of particular place-based resources.

Dynamic utilisation heatmaps are not risk adjusted as may be typically performed for quality measures. Since dynamic utilisation heatmaps have real representations of time and quantities, it is more challenging to risk-adjust using classic regression models.¹⁶ Alternatively, cohorts could be further separated by specific patient characteristics, because they were created on an individual patient level. Additionally, we focused on 54 NCI/NCCN centres because they set national standards for high-quality care; future work could analyse the community-based providers who provide care to most US patients with cancer.

In summary, our findings illustrate our ability to represent longitudinal and multidimensional EOL healthcare delivery as a heatmap image. These dynamic utilisation heatmaps are developed from the same administrative claims data used to calculate quality measures. They can elucidate the dynamic behaviours in EOL cancer care delivery in a reference frame closer to how clinicians conceptualise trajectories of care and thus how they think and make decisions about patient care. In future directions, we will develop multilayer heatmaps with each layer incorporating more detailed categories. Consequently, these rich heatmaps may provide actionable information for operational and clinical decision-making and highlight when and where such decisions impact care. Finally, we anticipate that a holistic understanding of care will also be of interest to researchers, as well as to patients and their families.

Author affiliations

¹The Dartmouth Institute for Health Policy & Clinical Practice and Biomedical Data Science, Dartmouth College Geisel School of Medicine, Hanover, New Hampshire, USA

²Department of Computer Science, Dartmouth College, Hanover, New Hampshire, USA

³The Dartmouth Institute for Health Policy & Clinical Practice, Dartmouth College Geisel School of Medicine, Hanover, New Hampshire, USA

⁴Section of Medical Oncology, Department of Medicine, Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire, USA

⁵Section of Palliative Care, Department of Medicine, Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire, USA

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Data availability statement Data are available in a public, open access repository. All hospital-level dynamic utilization heatmaps are freely available in the Dartmouth Dataverse at <https://doi.org/10.21989/D9/MTCDHG>.

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ORCID iDs

Inas S Khayal <http://orcid.org/0000-0001-8354-6006>

Gabriel A Brooks <http://orcid.org/0000-0003-3984-9995>

Amber E Barnato <http://orcid.org/0000-0003-1080-6270>

REFERENCES

- Wennberg J, Gittelsohn A. Small area variations in health care delivery: a population-based health information system can guide planning and regulatory decision-making. *Science* 1973;182:1102–8.
- Miesfeldt S, Murray K, Lucas L, *et al*. Association of age, gender, and race with intensity of end-of-life care for Medicare beneficiaries with cancer. *J Palliat Med* 2012;15:548–54.
- Skinner JS, Wennberg J. How much is enough? Efficiency and Medicare spending in the last six months of life. In: *The changing hospital industry: comparing not-for-profit and for-profit institutions*. University of Chicago Press, 2000: 169–94.
- Brooks GA, Li L, Sharma DB, *et al*. Regional variation in spending and survival for older adults with advanced cancer. *J Natl Cancer Inst* 2013;105:634–42.
- Earle CC, Landrum MB, Souza JM, *et al*. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol* 2008;26:3860–6.
- Levit LA, Balogh E, Nass SJ. *Delivering high-quality cancer care: charting a new course for a system in crisis*. Washington DC: National Academies Press, 2013.
- Ilinca S, Calciolari S. The patterns of health care utilization by elderly Europeans: frailty and its implications for health systems. *Health Serv Res* 2015;50:305–20.
- Zayas CE, He Z, Yuan J, *et al*. Examining healthcare utilization patterns of elderly middle-aged adults in the United States. *Proc Int Fla AI Res Soc Conf* 2016;2016:361–6.
- Nagin DS. *Group-Based modeling of development*. Harvard University Press, 2005.
- Iezzoni LI, Heeren T, Foley SM, *et al*. Chronic conditions and risk of in-hospital death. *Health Serv Res* 1994;29:435.
- Bach PB, Schrag D, Begg CB. Resurrecting treatment histories of dead patients: a study design that should be laid to rest. *JAMA* 2004;292:2765–70.

- 12 Wasp GT, Alam SS, Brooks GA, *et al.* End-Of-Life quality metrics among Medicare decedents at minority-serving cancer centers: a retrospective study. *Cancer Med* 2020;9:1911–21.
- 13 Berke EM, Smith T, Song Y, *et al.* Cancer care in the United States: identifying end-of-life cohorts. *J Palliat Med* 2009;12:128–32.
- 14 National Comprehensive Cancer Network. NCCN member institutions. Available: <https://www.nccn.org/members/network.aspx>. Published 2018 [Accessed 7 Mar 2019].
- 15 National Cancer Institute. Cancer center list. office of cancer centers. Published 2019. Available: <https://cancercenters.cancer.gov/Center/CClist> [Accessed 7 Mar 2019].
- 16 Goodman DC, Fisher ES, Morden NE. Quality of end-of-life cancer care for Medicare beneficiaries regional and hospital-specific analyses. *Health Aff* 2010;31:786–96.
- 17 End of life cancer care the Dartmouth Institute for health policy and clinical practice, the Dartmouth atlas project, 2020. Available: <https://www.dartmouthatlas.org/interactive-apps/end-of-life-cancer-care/>
- 18 VanderWeele TJ, Robinson WR. On the causal interpretation of race in regressions adjusting for confounding and mediating variables. *Epidemiology* 2014;25:473–84.
- 19 Cassandras CG, Lafortune S. *Introduction to discrete event systems*. Springer Science & Business Media, 2009.
- 20 Khayal IS, Farid AM. Architecting a system model for personalized healthcare delivery and managed individual health outcomes. *Complexity* 2018;2018:1–24.
- 21 Khayal IS, Farid AM. A dynamic system model for personalized healthcare delivery and managed individual health outcomes. *IEEE Access* 2021;9:138267–82.
- 22 Khayal IS, Zhou W, Skinner J. Structuring and visualizing healthcare claims data using systems architecture methodology. *World Acad Sci Eng Technol* 2017;11:342–6.
- 23 Schoonenberg WC, Khayal IS, Farid AM. *A Hetero-functional graph theory for modeling interdependent smart City infrastructure*. Springer International Publishing, 2019.
- 24 Gomes B, Calanzani N, Gysels M, *et al.* Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013;12:1–13.
- 25 Brazil K, Howell D, Bedard M, *et al.* Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliat Med* 2005;19:492–9.
- 26 Wennberg JE, Fisher ES, Goodman DC. *Tracking the care of patients with severe chronic illness*. The Dartmouth Atlas of Health Care, 2008.
- 27 Wennberg JE, Cooper MM. *The Dartmouth atlas of health care 1998*. Hanover, NH: Center for Evaluative Clinical Sciences, Dartmouth Medical School, 1998.
- 28 Ferrell B, Connor SR, Cordes A, *et al.* The National agenda for quality palliative care: the National consensus project and the National quality forum. *J Pain Symptom Manage* 2007;33:737–44.
- 29 Panzer RJ, Gitomer RS, Greene WH, *et al.* Increasing demands for quality measurement. *JAMA* 2013;310:1971–80.
- 30 Marshall DA, Burgos-Liz L, Pasupathy KS, *et al.* Transforming healthcare delivery: integrating dynamic simulation modelling and big data in health economics and outcomes research. *Pharmacoeconomics* 2016;34:115–26.
- 31 Sercu M, Beyens I, Cosyns M, *et al.* Rethinking end-of-life care and palliative care: learning from the illness trajectories and lived experiences of terminally ill patients and their family carers. *Qual Health Res* 2018;28:2220–38.
- 32 Lynn J, Adamson DM. Adapting health care to serious chronic illness in old age. In: *Living well at the end of life*. RAND Health, 2003.
- 33 Lunney JR, Lynn J, Foley DJ, *et al.* Patterns of functional decline at the end of life. *JAMA* 2003;289:2387–92.
- 34 Barnato AE, Farrell MH, Chang C-CH, *et al.* Development and validation of hospital "end-of-life" treatment intensity measures. *Med Care* 2009;47:1098–105.
- 35 Instructions for completing the data use agreement (DUA) form CMS-R-0235 2010, 2021. Available: <https://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/downloads/cms-r-0235.pdf> [Accessed 7 May 2021].
- 36 Wicks P, Mack Thorley E, Simacek K, *et al.* Scaling PatientsLikeMe via a "Generalized Platform" for Members with Chronic Illness: Web-Based Survey Study of Benefits Arising. *J Med Internet Res* 2018;20:e175.
- 37 Wicks P, Massagli M, Frost J, *et al.* Sharing health data for better outcomes on PatientsLikeMe. *J Med Internet Res* 2010;12:e19.
- 38 Turvey C, Klein D, Fix G, *et al.* Blue button use by patients to access and share health record information using the Department of Veterans Affairs' online patient portal. *J Am Med Inform Assoc* 2014;21:657–63.
- 39 Singh K, Meyer SR, Westfall JM. Consumer-Facing data, information, and tools: self-management of health in the digital age. *Health Aff* 2019;38:352–8.
- 40 Brennan N, Oelschlaeger A, Cox C, *et al.* Leveraging the big-data revolution: CMS is expanding capabilities to Spur health system transformation. *Health Aff* 2014;33:1195–202.
- 41 Casalino LP. The unintended consequences of measuring quality on the quality of medical care. *N Engl J Med* 1999;341:1147–50.
- 42 Rickerson E, Harrold J, Kapo J, *et al.* Timing of hospice referral and families' perceptions of services: are earlier hospice referrals better? *J Am Geriatr Soc* 2005;53:819–23.
- 43 Schockett ER, Teno JM, Miller SC, *et al.* Late referral to hospice and bereaved family member perception of quality of end-of-life care. *J Pain Symptom Manage* 2005;30:400–7.
- 44 Forum NQ. National voluntary consensus standards for quality of cancer care: national quality forum Washington, DC 2009.
- 45 Beaulieu-Jones BK, Orzechowski P, Moore JH. Mapping patient trajectories using longitudinal extraction and deep learning in the MIMIC-III critical care database. *Pac Symp Biocomput* 2018;23:123–32.
- 46 Graham LA, Wagner TH, Richman JS, *et al.* Exploring trajectories of health care utilization before and after surgery. *J Am Coll Surg* 2019;228:116–28.
- 47 Morden NE, Chang C-H, Jacobson JO, *et al.* End-Of-Life care for Medicare beneficiaries with cancer is highly intensive overall and varies widely. *Health Aff* 2012;31:786–96.
- 48 Wennberg JE, Fisher ES, Stukel TA, *et al.* Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. *BMJ* 2004;328:607.
- 49 Kline R, Adelson K, Kirshner JJ, *et al.* The Oncology Care Model: Perspectives From the Centers for Medicare & Medicaid Services and Participating Oncology Practices in Academia and the Community. *Am Soc Clin Oncol Educ Book* 2017;37:460–6.
- 50 Griffin PM, Nembhard HB, DeFlicht CJ. *Healthcare systems engineering*. John Wiley & Sons, 2016.
- 51 Roelens B, Poels G. The creation of business architecture heat maps to support strategy-aligned organizational decisions. In: *8th European conference on is management and evaluation ECIME*. Academic Conferences and Publishing International Limited, 2014: 388–92.
- 52 Lather JI, Messner JI. Framework for a hybrid simulation approach for an integrated decision support system in healthcare facilities. In: *2018 winter simulation conference WSC*, 2018: 1406–17.
- 53 Klein RW, Dittus RS, Roberts SD, *et al.* Simulation modeling and health-care decision making. *Med Decis Making* 1993;13:347–54.
- 54 Fakhimi M, Probert J. Operations research within UK healthcare: a review. *J Ente Infor Mana* 2013;26:1–2.
- 55 Denton BT. *Handbook of healthcare operations management*. New York: Springer, 2013: 10. 9.
- 56 Brandeau ML, Sainfort F, Pierskalla WP. *Operations research and health care: a Handbook of methods and applications*. Springer Science & Business Media, 2004.