MASSACHUSETTS
HEALTH POLICY COMMISSION

SEPTEMBER 30, 2020

HPC POLICY BRIEF

Serious Illness Care in Massachusetts: Differences in care received at the end of life by race and ethnicity

In MA and the U.S., Black Medicare beneficiaries are **more likely** than non-Black beneficiaries to be hospitalized in the last six months of life and, if they are **hospitalized**, they are **substantially more likely** than non-Black beneficiaries to receive care in the **ICU/CCU.**

INTRODUCTION

High quality serious illness care addresses medical and emotional needs, with patients receiving care based on their individual preferences and priorities. However, numerous challenges, including lack of information, poor communication, clinician-driven practice patterns, and the cumulative effects of institutional racism often drive a disconnect between best practices and care received, particularly for people of color and people with lower income or education.[1,2] A Massachusetts survey in 2018 found that 29% of people with a loved one who died in the past year, and fully 41% of respondents of color,[i] said that health care providers did not fully follow the deceased person's wishes.[3] Previous HPC research has documented extensive variation in end-of-life care that is unlikely to be driven by patient preferences, but few studies have specifically examined intensity of service use at the end of life in Massachusetts by race/ethnicity.

This brief examines care at the end of life for Medicare beneficiaries in Massachusetts by race/ethnicity, including service intensity and hospice use, and also presents early trends in the use of a new Medicare service code for advance care planning. Particularly in light of the COVID-19 pandemic and its exposure of health inequalities, the importance of early conversations about preferences of care for all patients has only increased.

DATA SOURCES

The HPC used publicly available fee-for-service (FFS) Medicare data available through 2017 to examine service use at the end of life and claims for advance care planning in Massachusetts and in other states. Sources included Medicare Public Use Files for hospice and advanced care planning analysis, as well as Dartmouth Atlas Project data for service use in the last six months of life.[4] Results from the Dartmouth Atlas Project are adjusted for age, sex, and race, where appropriate. The HPC used terminologies for racial and ethnic groups as they appeared in the data sources, which differ in their categorization and language.

RESULTS

Intensity of hospital use in the six months before death

Medicare decedents in Massachusetts have somewhat higher hospital use but less intensive care unit or cardiac care unit (ICU/CCU) use in the last six months of life than the U.S. average (**Exhibit 1**). Massachusetts Medicare beneficiaries who died in 2017 had an average of 1.34 hospitalizations per decedent in the last six months of life, compared to an average of 1.27 hospitalizations nationally while Massachusetts Medicare beneficiaries spent over a third (38%) fewer days in the ICU/CCU compared to the national average (an average 2.16 days and 3.45 days per decedent, respectively). Yet in both Massachusetts and the U.S., Black Medicare beneficiaries are more likely than non-Black beneficiaries to be hospitalized in the last six months of life and, if they are hospitalized, they are substantially more likely than non-Black beneficiaries to receive care in the ICU/CCU. In Massachusetts, Black beneficiaries had 14% more hospital admissions than non-Black beneficiaries, compared to 25% more in the U.S. overall. In terms of ICU/CCU days, Black beneficiaries in Massachusetts had 33% more days on average than non-Black beneficiaries, compared to 52% more nationally. These findings are consistent with prior literature showing that in the U.S. overall, Black and Hispanic Americans are significantly more likely to die in a hospital and receive more intensive treatment at the end of life than White Americans.[5]

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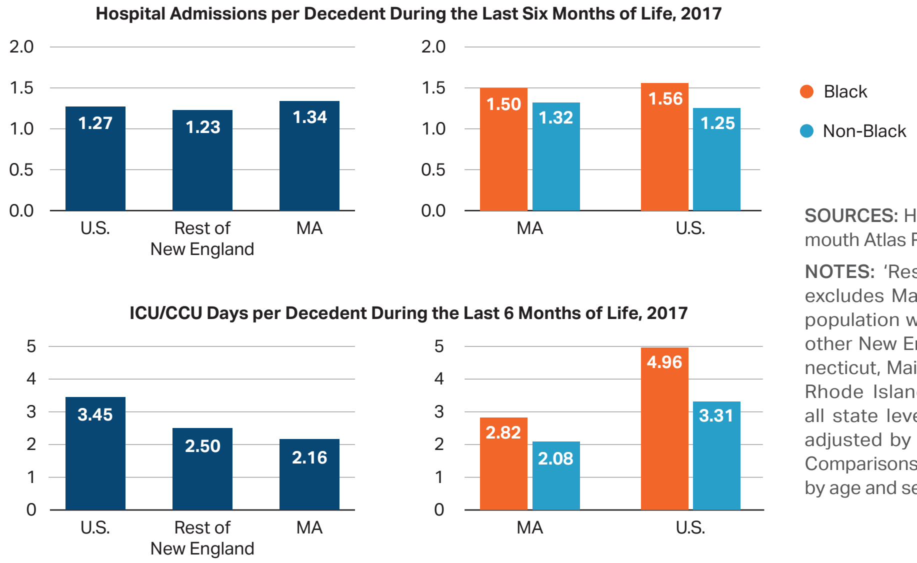
[i] Due to sample size limitations, this difference was not statistically significant at the 5% level in the 2018 survey. A 2016 version of the survey found a larger and statistically significant difference on this measure by race (69% of non-White versus 43% of White respondents). See: Massachusetts Coalition for Serious Illness Care. Massachusetts Survey on Advance Care Planning and Serious Illness Care: Spring 2016 Survey of Massachusetts Residents. 2016. Available at: http://maseriouscare.org/uploads/Coalition-Commitments-and-Survey.compressed.pdf

Surveys have found that less than 10% of U.S. adults would prefer to die in the hospital. However, **rates of death** occurring in the hospital are more than **double** that figure nationally (20.2%) and are **higher** still in MA (23.0%).

Exhibit 1: Hospital admissions and ICU/CCU days per decedent, 2017



SOURCES: HPC analysis of Dartmouth Atlas Project data, 2017

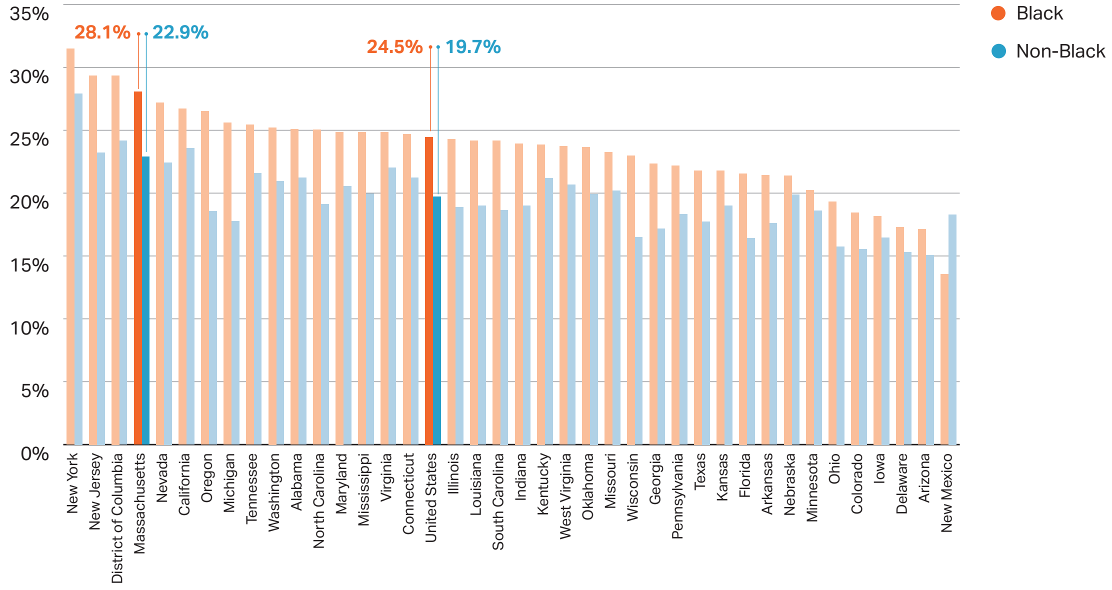
NOTES: 'Rest of New England' excludes Massachusetts and is population weighted among the other New England states (Connecticut, Maine, New Hampshire, Rhode Island, Vermont). Overall state level comparisons are adjusted by age, sex, and race. Comparisons by race are adjusted by age and sex.

Death in the hospital

Surveys have found that less than 10% of U.S. adults would prefer to die in the hospital.[6] However, rates of death occurring in the hospital are more than double that figure nationally (20.2%) and are higher still in Massachusetts (23.0%). In fact, Massachusetts had the 4th highest rate of dying in the hospital among Black beneficiaries (28.1%), the 5th highest rate for all others (22.9%), (**Exhibit 2**) and a gap between Black and non-Black beneficiaries (5.2 percentage points) that ranked as the 11th highest difference among states with data available by race.

Massachusetts had the **4th highest rate** of dying in the hospital among Black beneficiaries (28.1%), the **5th highest rate** for all others (22.9%).

Exhibit 2: Percentage of Medicare deaths occurring in the hospital, by state and Black vs. non-Black beneficiaries, 2017



SOURCES: HPC analysis of Dartmouth Atlas data, 2017

NOTES: United States bars include Puerto Rico, but these data are not shown separately. Twelve states do not have data available on race and are not shown in this figure. The states without available data to include in the figure are Alaska, North Dakota, Vermont, Hawaii, New Hampshire, Maine, South Dakota, Rhode Island, Wyoming, Idaho, Montana, Utah. Comparisons by race are adjusted by age and sex.

47.1%

of MA Medicare beneficiaries who died in 2017 were **enrolled in hospice** at the time of their death, the **32nd highest rate** among states.

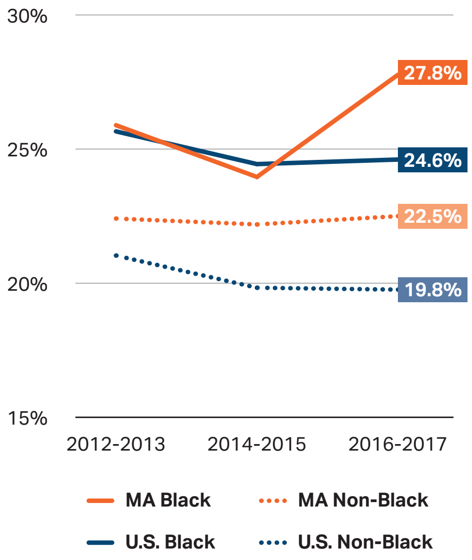
While the percentage of Medicare deaths that occur in the hospital has been declining since 2012 in the U.S. overall and in the rest of New England, the percentage has increased slightly in Massachusetts during this time period, particularly among Black beneficiaries, resulting in a widening gap (**Exhibit 3**).

This higher service use translates to higher health care spending. Inpatient spending per Medicare FFS decedent during the last six months of life was 20% higher in Massachusetts ($19,928) compared to the U.S. overall ($16,585) in 2017. Some higher intensity care may reflect patient preferences and the delivery of high-quality care; however, providing high intensity services that are not consistent with patient preferences unnecessarily increases total health care spending.

Hospice use rates

Hospice is a comprehensive palliative care service with the goal of addressing pain and other symptoms while providing emotional support for the patient and their caregivers. Care is typically provided in the patient's home (or nursing home) but can also be delivered in a hospital or freestanding unit. Medicare eligibility for hospice requires that patients forgo curative services and that a doctor certify that the patient has less than six months to live, although eligibility can be extended. Hospice care is associated with less pain and higher rated quality of care.[7] While there is not an explicitly defined duration of hospice service to maximize quality, longer enrollment in hospice is associated with higher quality of care for patients and the experience of their surviving caregivers. Enrollment in hospice for a week or less is generally not considered to maximize the benefit of hospice to the patient and family.[8]

Exhibit 3: Percentage of Medicare deaths occurring in the hospital, U.S. and Massachusetts, by Black versus non-Black beneficiaries, 2012 – 2017



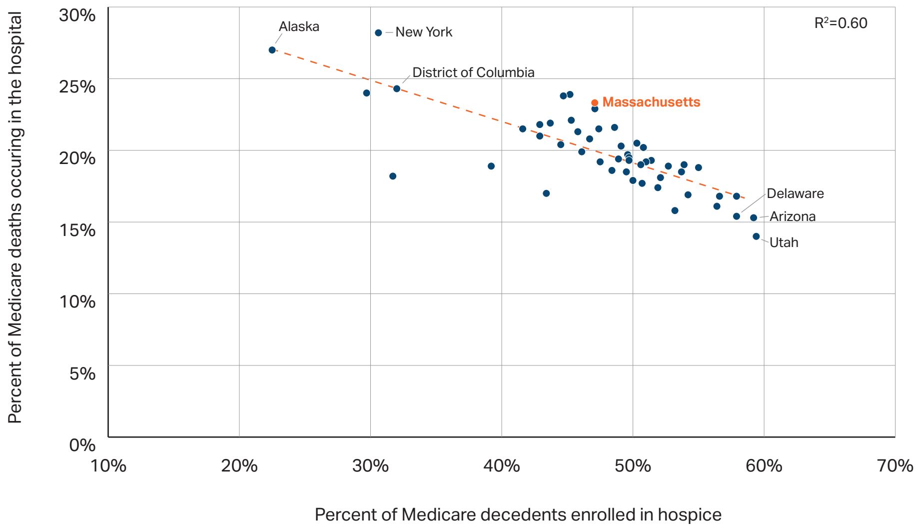
SOURCES: HPC analysis of Dartmouth Atlas data, 2012-2017

NOTES: Comparisons by race are adjusted by age and sex.

Based on data from the National Hospice and Palliative Care Organization, 47.1% of Massachusetts Medicare beneficiaries who died in 2017 were enrolled in hospice at the time of their death, the 32nd highest rate among states and lower than the national average of 48.2% (Utah had the highest share at 59.4%).[9] Use of hospice and the percentage of deaths occurring in the hospital are strongly correlated (R^2 = 0.60) (**Exhibit 4**).

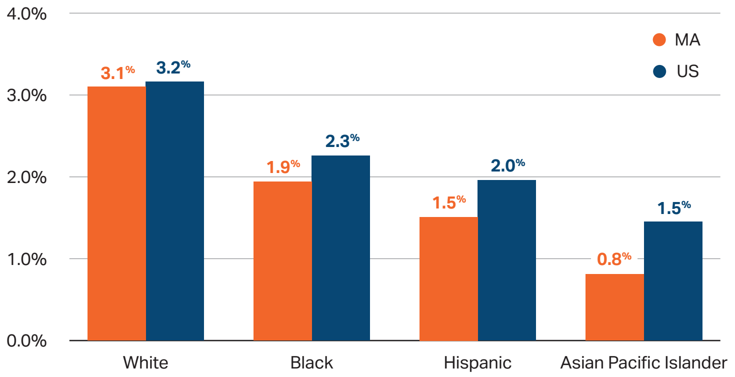
Use of **hospice** and the **percentage of deaths** occurring in the hospital are **strongly correlated.**

Exhibit 4: Correlation between percentage of Medicare deaths occurring in the hospital and percentage of beneficiaries enrolled in hospice at the time of death, 2017



SOURCES: HPC analysis of Dartmouth Atlas data (percentage of Medicare deaths in the hospital) and National Hospice and Palliative Care Organization data (percentage of decedents enrolled in hospice at the time of death), 2017.

Exhibit 5: Percent of all Medicare beneficiaries using hospice, by race, Massachusetts vs U.S., 2017



SOURCES: HPC analysis of CMS PAC public use file, Medicare enrollment state tables, and KFF demographic data, 2017.

NOTES: Because Medicare FFS covers hospice services for beneficiaries enrolled in either FFS or Medicare Advantage, this figure includes FFS and Medicare Advantage in the numerator and denominator. Figure includes all beneficiaries, not only those eligible for hospice services.

Use of hospice in Massachusetts was lower than in the U.S. overall in all racial groups for which data was available (**Exhibit 5**). Among all Medicare beneficiaries in Massachusetts, use was substantially lower among Black (1.9%), Hispanic (1.5%), and Asian/Pacific Islander (0.8%) beneficiaries compared to White beneficiaries (3.1%). Potential reasons for these differences include preferences for more aggressive care, mistrust of the health care system, and miscommunication and misunderstanding of treatment options.[10]

Among Medicare decedents who did use hospice, about one-quarter used the service for only one week or less (i.e. a scenario in which patients are unlikely to benefit fully from the program) in both Massachusetts (24%) and the U.S. (26%) in 2017. Overall, Massachusetts had the 33rd highest share of hospice enrollees who used the service for 7 days or less, reflecting some relative success on this metric.

High proportions of MA residents do not receive care at the end of life in accordance with their wishes, **more are hospitalized** at the end of life than in most other states, **more die in the hospital**, and **fewer** take advantage of the **hospice benefit**. Each of these outcomes are exacerbated for **residents of color.**

In summary, high proportions of Massachusetts residents do not receive care at the end of life in accordance with their wishes, more are hospitalized at the end of life than in most other states, more die in the hospital, and fewer take advantage of the hospice benefit. Each of these outcomes are exacerbated for residents of color. The findings presented here of higher intensity service use among Black patients compared to non-Black patients in the U.S. overall are consistent with numerous studies.[11]

While substantial variation in intensity of service use throughout the U.S. is most strongly associated with health system characteristics and provider practice patterns than differences in patient characteristics,[12] individual preferences for care at the end of life also play an important role. Black and Hispanic patients are more likely than White patients to prefer more intensive care, although large majorities in all groups express preferences for less intensive care.[13] Differences are influenced by a number of cultural and socioeconomic factors associated with preferences for more intensive care, including greater religiousness, living alone, knowledge of options, perceptions of the effectiveness of treatments, not having a regular doctor, and distrust of the health care system.[13] Black patients are more likely to believe that they would receive lower quality treatment if they completed an advance directive (such as a document stating preferences for care at the end of life; see following section), stemming from historic mistreatment by the medical system and concerns based on receiving lower quality care and worse access throughout life.[12]

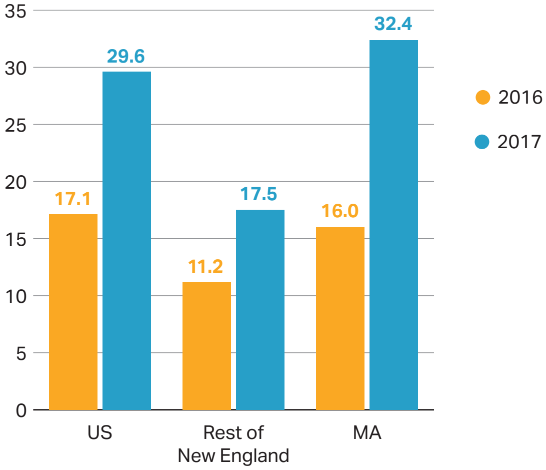
The interaction between patient preferences and provider practice patterns is complex. For example, patients of color are less likely to be informed about different end-of-life care options, potentially resulting in greater influence of individual clinician and local practice patterns.[14,15] One study across four large urban hospitals in Chicago with inpatient palliative care programs found little influence of race/ethnicity on death in hospital or hospice use when controlling for care site, reinforcing the importance of institutional differences versus patient preferences.[16] Previous HPC research has documented significant variation in measures of intensity of certain end-of-life services within Massachusetts that is unlikely to be explained by differences in patient preferences. For example, hospice enrollment in the last year of life among Medicare decedents with poor prognosis cancer varied 1.7 times between regions in Massachusetts in 2012 (from 47% to 83%).[17] The large variation observed in measures of service intensity at the end of life between states and by race/ethnicity indicates a need for improvement to ensure that all patients receive high quality care based on their preferences.

ADVANCE CARE PLANNING

Planning in advance for end-of-life care is a central part of ensuring patient-centered care. Patients can discuss advance care planning (ACP) with their provider, and can include family members in the discussion, to help make informed choices about the care they would want to receive. These conversations can ideally eventually result in documentation of patient preferences, known as advance directives. Advance directives can include a living will (a legal document providing instructions on whether to use treatments such as ventilators, tube feeding, and resuscitation), designation of a health care proxy, and filling out a medical order for life sustaining treatment (MOLST) form.[ii]

Research has found that early communication about preferences between patients and clinicians leads to higher quality care; aspects of communication that have been found to impact outcomes include addressing emotional and spiritual needs, prognostic awareness, treatment options, goals for care, and costs of care.[18] However, only 27% of adults in Massachusetts with a serious health condition reported having a conversation with a health care provider about end-of-life care wishes.[3] While the share of adults who report having these conversations with a provider did not vary significantly by race/ethnicity, more data is needed on the quality and comprehensiveness of these conversations. Studies also suggest that people of color are less likely than White adults to have named a health care proxy or documented their wishes for medical care.[3, 19] A Kaiser Family Foundation study found that among older adults in the U.S. with serious illness, 65% of White adults had documented wishes for medical care, compared with 38% of Black adults and 41% of Hispanic adults.[20]

Exhibit 6: Advance care planning per 1,000 FFS Medicare beneficiaries, 2016 – 2017



SOURCES: HPC analysis of Medicare State and National HCPCS Aggregate Data, CY2016 & CY 2017

NOTES: Data represent unique beneficiary interactions coded using CPT 99497 in either an office or facility setting.

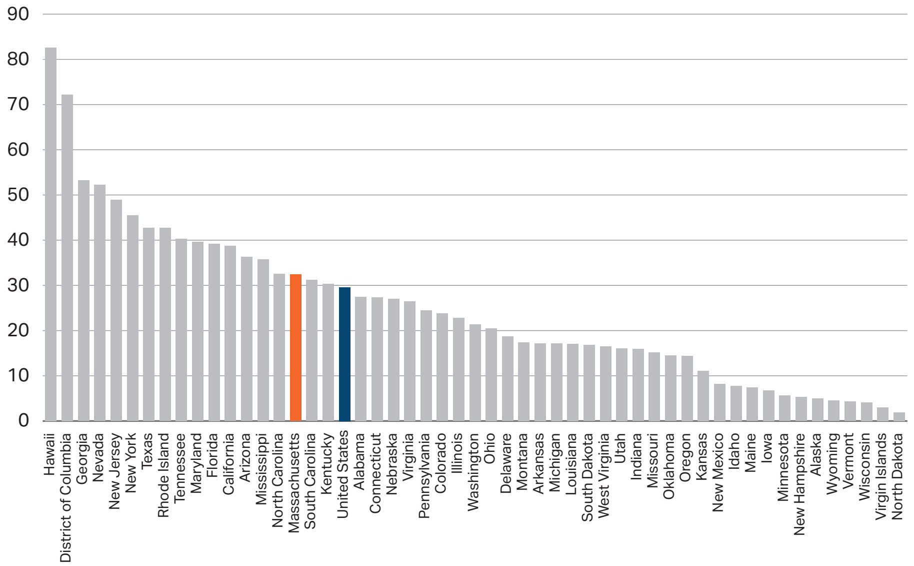
Advance care planning discussions in the MA Medicare population **doubled** from **16.0 to 32.4** services per 1,000 FFS beneficiaries in the **first years** of a **new Medicare service code.**

Medicare reimbursement for advance care planning

To support these advance care discussions, Medicare began reimbursing providers specifically for ACP in January 2016. The Center for Medicare & Medicaid Services' (CMS) service description includes "the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed)." Services include initial ACP discussion (CPT 99497) and subsequent ACP discussion (CPT 99498). This analysis focuses on intial ACP discussion to investigate uptake in unique beneficiaries. ACP may occur without a provider billing for the discussion, so the rates of discussions reflected in claims are likely an underestimate. Furthermore, claims for ACP do not inform the quality of the discussion.

Use of ACP services in the Massachusetts Medicare population grew from 16.0 to 32.4 services per 1,000 FFS beneficiaries between 2016 and 2017 (102%), a larger increase than in the U.S. overall (73%) and in the rest of New England (56%) (**Exhibit 6**). In 2017, Massachusetts ranked 16th in the nation for the rate of ACP services (**Exhibit 7**).

Exhibit 7: Advance care planning per 1,000 FFS Medicare beneficiaries, 2017



SOURCES: HPC analysis of Medicare State and National HCPCS Aggregate Data, CY 2017

NOTES: Data represent unique beneficiary interactions coded using CPT 99497 in either an office or facility setting.

[ii] MOLST is a set of medical orders for specific life-sustaining treatments intended to instruct health care providers and may be documented both in electronic medical records and in portable form for emergency responders.

With **health equity considerations** in mind, health systems should **continue to support** clinicians to engage in **advance care planning** with all patients, including **increasing training** in ACP, **cultural competency**, and providing **language resources.**

Nevertheless, absolute rates of ACP services were still quite low, with only a small percentage of Medicare beneficiaries engaging in these services in Massachusetts and nationwide.

The number of unique providers in Massachusetts who had an initial ACP discussion grew by 47% from 2016 to 2017, similar to the national growth rate of 49% more providers billing for these services.[iii] The large majority of providers who billed for an initial ACP discussion in Massachusetts were primary care providers, a positive finding to support care coordination. The top three provider types in Massachusetts in 2017 were internal medicine physicians (42.1%), nurse practitioners (28.6%), and family practice physicians (14.0%).

While the data available to the HPC for ACP services do not contain patient demographics, literature suggests that providers are less likely to initiate ACP with patients of color. A study of ACP use in 2016 in New England found that Black, Hispanic, and Asian Medicare beneficiaries were significantly less likely than White beneficiaries to have a claim for an ACP discussion.[21, iv] However, early national data suggests that increases in ACP discussions were greater among Black beneficiaries compared to White beneficiaries.[22]

Clinician perspectives and resources play a critical role in ACP. In a study of clinicians from six health systems in the U.S., characteristics of patients with whom clinicians stated they had difficulty discussing ACP included racial and ethnic minorities (31%), non-English speakers (24%), and religious patients (14%).[23] Clinicians described avoiding ACP with patients in these groups due to perceiving that the patients would be reluctant to discuss dying, as well as to their own discomfort. However, clinician approaches that facilitated ACP with these patient groups included rejecting stereotypes and assessing individual preferences, believing that proficiency in ACP with all patients is a professional obligation, and not assigning value to particular ACP outcomes (for example, not viewing a resulting advance directive to provide full CPR as a "failure").

OPPORTUNITIES TO ADVANCE ACP IN MASSACHUSETTS

Massachusetts providers and other stakeholders have taken steps to promote ACP and ensure that patients' wishes are documented and honored. More than one hundred organizations have come together to form the Massachusetts Coalition for Serious Illness Care, including providers, payers, consumer advocates and state agencies.[24] Recently, the Coalition partnered with The Conversation Project and others to develop tools in response to the COVID-19 pandemic.[25]

Massachusetts providers have made efforts to document patients' goals and preferences for care. Through the HPC's Accountable Care Organization (ACO) Certification Program, the HPC collected information about processes regarding advanced illness care, such as the integration of ACP into clinical processes.[26, v] As of 2017, most Massachusetts ACOs (16) reported having processes for ACP and for identifying patients for palliative care. Many ACOs (10) reported that they provide training for clinicians on ACP. Additionally, most ACOs (16) reported having ACP included in their electronic health record, and 13 ACOs reported having written agreements with advanced illness, palliative, and hospice care providers.

While stakeholders and providers in Massachusetts have made notable progress, several actions can further support quality improvement in serious illness care for all populations in Massachusetts, a particularly crucial goal in the context of the COVID-19 pandemic. With health equity considerations in mind, health systems should support clinicians to engage in ACP with all patients, with a particular focus on reaching consistency in initiation of ACP for patients of color and White patients and increasing training in ACP, cultural competency, and providing language resources to be able to deliver ACP effectively for all patient populations.

In addition, health system and policy leaders in Massachusetts should continue their momentum to facilitate conversations between family and loved ones and support a range of strategies to support advance directives before patients experience serious illness. These efforts are particularly important in situations when health status can change quickly, and presently, when existing hospital infection control protocols to prevent spread of COVID-19 may severely restrict in-person communication. Continued quantitative and qualitative data monitoring – from claims, survey data, and patient perspectives – are essential to support high quality equitable care for all populations at the end of life.

[iii] The number of unique providers grew from 1,076 in 2016 to 1,581 in 2017. The Medicare Public Use Files sum the unique providers who billed in office versus facility settings separately. Therefore, double counting of providers between the two settings is possible but is likely minimal based on comparison to literature using different data sets.

[iv] Adjusting for age, gender, income, dual eligibility for Medicare and Medicaid and state of residence, being Black, Hispanic, and Asian were associated with lower odds of having a claim for ACP services (0.63, 0.40, and 0.84, respectively).

[v] This data was only collected for the 17 ACOs that applied for certification in 2017 under the ACO Certification program's 2017 standards.

POLICY BRIEF PREPARED BY:
Sara Sadownik
Deputy Director, Research and Cost Trends

Hannah James
Senior Research Associate, Research and Cost Trends

Dr. David Auerbach
Director, Research and Cost Trends

ACKNOWLEDGEMENTS:
Courtney Anderson
Jasmine Bland
Vivian Haime
Lois Johnson
Coleen Elstermeyer

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