



---

# Minnesota Palliative Care Advisory Council

ANNUAL LEGISLATIVE REPORT

02/14/2021

## **Minnesota Palliative Care Advisory Council Annual Legislative Report**

Minnesota Department of Health  
Comprehensive Cancer Control Program  
PO Box 64882  
St. Paul, MN 55164  
651-201-5094  
health.compcancer@state.mn.us  
[www.health.state.mn.us](http://www.health.state.mn.us)

As requested by Minnesota Statute 3.197: This report cost approximately \$3,500 to prepare, including staff time, printing and mailing expenses.

*Upon request, this material will be made available in an alternative format such as large print, Braille or audio recording.  
Printed on recycled paper.*

## Contents

Minnesota Palliative Care Advisory Council .....	1
Executive Summary .....	4
The Definition of Palliative Care .....	7
Palliative Care, Medicaid and MinnesotaCare .....	9
Palliative Care and Serious Illness During the Pandemic .....	14
Palliative Care and Health Equities.....	15
Palliative Care and the Transportation Divide.....	22
Palliative Care and the Digital Divide .....	25
Palliative Care and Reimbursement .....	27
Conclusion .....	30
Appendix A: Summary of 2021 Key Recommendations.....	32
Appendix B: The Council’s 2020 Recommendations.....	32
Appendix C: Medicaid Reimbursement by State.....	33
Appendix D: Palliative Care and the way to health equity: what the Council is reading .....	36
Appendix E: Minnesota Rural Urban Commuting Codes (RUCA) Explained.....	38
Appendix F: Council Members.....	39

## Executive Summary

The Minnesota Legislature established the Minnesota Palliative Care Advisory Council (the Council) in 2017 under Minnesota Statutes, section 144.059. The Council is charged with assessing, analyzing, and making recommendations to the legislature on issues related to palliative care in Minnesota. The Council is required to report on its progress by February 15 of each year.

This report:

- Provides information about the Palliative Care Advisory Council's work in 2020.
- Provides information about palliative care.
- Details the Council's policy recommendations, which will be the foundation for its work in 2021.

History will certainly record 2020 as a horrible year for Minnesota and the world. While the year began like any other year, with Minnesotans wondering about the next winter storm, a different storm was brewing as the Novel Coronavirus spread across the world and into the US.

January faded into February, and amid growing concerns, the Council held its annual in person planning meeting on February 25, 2020. On March 6, Minnesota announced its first presumptive case of the coronavirus; on March 8, its second case. By March 11, the World Health Organization declared the virus a pandemic; the University of Minnesota suspended all in-person classes until at least April 1. Governor Walz closed all schools on March 15, and a day later, the Governor ordered the closure of all public places. The first Minnesota death was reported March 21.

As schools and public places closed, everyone's focus shifted from 'normal' to 'distance' to social distance, (at least six feet apart), to distance learning as schools adopted online learning options, to distance work for those jobs that could be done remotely.

On April 1, Minnesota reported 689 confirmed cases and 17 deaths; by April 30, confirmed cases rose to 5,136 with 343 deaths.

On May 25, the day of George Floyd's death, there were 21,315 confirmed cases and 881 deaths in Minnesota. Minnesota became the flash point for civil unrest throughout the nation and the world.

Both the pandemic and the civil unrest highlighted inequities in the health system and the criminal justice system.

On November 18, Governor Walz said in a televised address that the lockdown Minnesotans endured last spring had made a difference, and that another pause was needed to protect Minnesota's health care system, now at a breaking point. While the state had built up its bed capacity and supplies of personal protective equipment since the first lockdown, he said, doctors, nurses and other care staff are now increasingly falling ill because of community spread.<sup>1</sup>

By December 31, Minnesota reported the following COVID-19 statistics, cumulative since the beginning of the pandemic<sup>2</sup>:

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

- 5,574,962 COVID-19 tests completed
- 415,302 confirmed cases
- 32,194 health care workers testing positive
- 5,323 deaths
- 3,431 of the deaths within congregate care facilities
- 21,864 persons hospitalized
- 4,620 ICU beds occupied

Minnesotans have learned to not take their own health, the health care systems, and health care workers for granted ever again.

During the February 25 retreat, the Council discussed concerns with how to get the work of the Council done as a completely volunteer Council, because Minnesota's 2020 budget included no funding to support the Council. To help focus the work of the Council, the Palliative Care Advisory Council reviewed its nineteen recommendations on palliative care in its 2020 annual report. Those recommendations covered raising awareness, education and training, reimbursement, sustainability, and delivery models, research, data, and metrics, and standards of practice. During its retreat, the Council identified the following five recommendations as its top priorities in 2020:

1. Ensure that palliative care benefits offered by private and public payers are comprehensive and support the full interdisciplinary team.
2. Require a minimum number of hours of instruction in primary palliative care and pain management through state health professional licensure and continuing education guidelines for those who have Minnesota state licensure (Physician, Advanced Practice Provider, Registered Nurse).
3. Establish a clear definition for palliative care in state statute and relevant regulations, independent of hospice regulations.
4. Fund a statewide public education campaign around serious illness.
5. Require state regulatory agencies to collect data, and report on palliative care access and quality. Measures should include disparities in access and utilization of palliative care across populations, care settings, and geography.

While the Council had a plan at the end of the February retreat, we did not, could not, anticipate the reality of 2020. The Council, individually, professionally, and collectively adjusted our lives in response to the ever shifting landscape of stay at home orders, masking, social distancing, remote learning, working remotely, group communication technologies, and wondering if the cough was just a cough, or the beginning of COVID-19.

What follows is the Minnesota Palliative Care Advisory Council's 2021 annual report to the Commissioner of Health and the Legislature. While the Council has not forgotten the nineteen recommendations presented in 2020, this Annual Report describes our attention to the five priorities listed above and our recommendations: an improved definition of 'palliative care' to inform state statute and regulations; public education focused on decision-making, serious illness and the role of palliative care; payers' reimbursement for comprehensive palliative care benefits; and the multiple access barriers to palliative care. In addition to its attention to inequities in access to palliative care, the Palliative Care Advisory Council has studied and deepened its commitment to call out and respond to the glaring, painful realities of health disparities. Access to affordable and comprehensive healthcare that includes palliative care is a step in the right direction but falls far short of

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

addressing the systemic conditions essential to achieve health equity. The Council will continue to study and provide leadership in promoting health equity through its broad-based membership.

*(Note: The Council's recommendations for improving the availability of and accessibility to Palliative Care are included at the end of each section. As some recommendations may overlap between sections, a summary of the Council's key recommendations can be found in Appendix A.)*

---

<sup>1</sup> [Minnesota shuts more businesses as COVID-19 spread soars \(https://apnews.com/article/sports-youth-sports-minnesota-coronavirus-pandemic-restaurants-e366188e391c858260764c8f56a713d6\)](https://apnews.com/article/sports-youth-sports-minnesota-coronavirus-pandemic-restaurants-e366188e391c858260764c8f56a713d6)

<sup>2</sup> [Situation Update for COVID-19 - Minnesota Department of Health \(https://www.health.state.mn.us/diseases/coronavirus/situation.html\)](https://www.health.state.mn.us/diseases/coronavirus/situation.html)

## The Definition of Palliative Care

“Palliative care is now a recognized medical subspecialty, but experts in the field say **lack of knowledge** about it **within the general public, and even among medical providers**, is impeding the many benefits of these services for those who most need them.”<sup>1</sup>

The definition of palliative care varies from state to state. According to The National Academy for State Health Policy (NASHP) “approximately 50 percent of states define palliative care in some way, and/or incorporate standards for palliative care in regulation.” That said, **how and where palliative care is defined in statute and specified in regulation matter**. Most states *[including Minnesota]* define palliative care within the context of hospice licensure or regulation, limiting the definition and standards to services provided to those with a terminal illness who have elected hospice.”<sup>2</sup>

While palliative care is a key component of excellent hospice care, it is also a key component of excellent health care in general. Placing palliative care within hospice statutes contributes to a misunderstanding, by members of both the public and the healthcare community, that palliative care is only associated with hospice care. While both palliative care and hospice care are designed to deliver comfort and relief to patients and families, they differ in critical ways. Hospice focuses on comprehensive end of life care, of which palliative care is a crucial component. **Hospice is generally for individuals anticipated to have six months or fewer to live** and who are no longer receiving active *[curative]* treatment.<sup>3</sup> In contrast, **Palliative care provides essential support at any age or stage of serious illness or condition, often together with curative treatment.**<sup>4</sup> Palliative care is focused on providing relief from the symptoms and stress of a serious illness or condition. Because it is not confined to hospice care, palliative care must be appropriately located in state statute and regulation.

So how and where does Minnesota define palliative care? Minnesota’s definition of palliative care is found in Statute 144.75A which provides definitions and service requirements for hospice.

### **Subdivision 8 of this statute defines hospice services or hospice care as:**

*"Hospice services" or "hospice care" means **palliative** and supportive care and other services provided by an interdisciplinary team under the direction of an identifiable hospice administration **to terminally ill hospice patients and their families** to meet the physical, nutritional, emotional, social, spiritual, and special needs experienced during the final stages of illness, dying, and bereavement, or during a chronic, complex, and life-threatening illness contributing to a shortened life expectancy for hospice patients who meet the criteria in subdivision 6, clause (2). These services are provided through a centrally coordinated program that ensures continuity and consistency of home and inpatient care that is provided directly or through an agreement.*

### **Subdivision 12 further defines palliative care as:**

*"Palliative care" means the total active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families.*

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

The statement in Subdivision 12, ***“Palliative care” means the total active care of patients whose disease is not responsive to curative treatment***, is an inaccurate characterization of palliative care. In palliative care, you do not have to give up treatment that might cure a serious illness. Palliative care is symptom management that may begin at the time of diagnosis, be required for life-long management of a chronic condition or can be provided along with curative treatment.

The Council supports the recommendation made by the National Academy for State Health Policy to improve palliative care by “creating standards and definitions within state licensing and regulation.”

To clarify what palliative care is, the Palliative Care Advisory Council recommends the following actions:

**KEY RECOMMENDATION:** Consider revising the language in 144.75A Subdivision 12 to **eliminate the exclusive association of palliative care with hospice care.**

**KEY RECOMMENDATION:** Adopt the definition of Palliative Care for Minnesota as follows:

*“Palliative care is specialized medical care for people living with a serious illness or life-limiting condition. This type of care is focused on providing relief from the symptoms and stress of a serious illness or condition. The goal is to improve quality of life for both the patient and the family. Palliative care is the relief of pain and suffering for individuals living with serious illness or condition. It’s a team-based approach, providing essential support at any age or stage of serious illness or condition, often together with curative treatment.”<sup>4</sup>*

---

<sup>1</sup> [Palliative Care Is Not Just for Hospice Patients \(https://www.nextavenue.org/confusion-palliative-vs-hospice-care/\)](https://www.nextavenue.org/confusion-palliative-vs-hospice-care/)

<sup>2</sup> [Palliative Care: A Primer for State Policymakers \(https://www.nashp.org/wp-content/uploads/2019/05/Palliative-Care-A-Primer-for-State-Policymakers.pdf\)](https://www.nashp.org/wp-content/uploads/2019/05/Palliative-Care-A-Primer-for-State-Policymakers.pdf)

<sup>3</sup> [Palliative Care Is Not Just for Hospice Patients \(https://www.nextavenue.org/confusion-palliative-vs-hospice-care/\)](https://www.nextavenue.org/confusion-palliative-vs-hospice-care/)

<sup>4</sup> Based on the Center to Advance Palliative Care definition

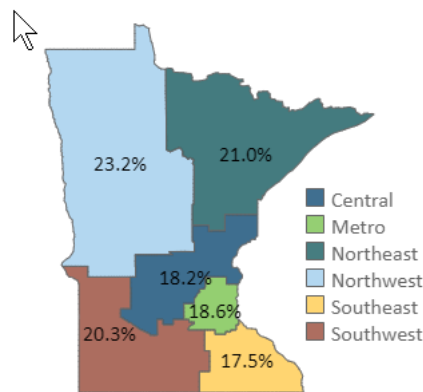


## Palliative Care, Medicaid and MinnesotaCare

According to the Minnesota Department of Health website, both Minnesota’s Medicaid, known as Medical Assistance, and MinnesotaCare provide essential health care to people across Minnesota. Medical Assistance is for people with low income and may require small co-pays for some services. MinnesotaCare is a program for Minnesotans with low income who do not have access to affordable health care coverage. MinnesotaCare may require a monthly premium, which is based on household size and income.<sup>1</sup>

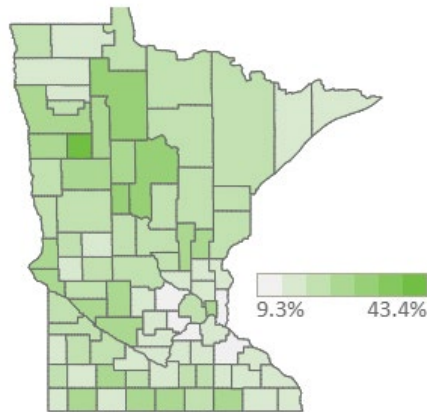
Enrollment in Medical Assistance has remained consistent since 2015, with about 1.1 million people covered. Medical Assistance serves more than half a million children each year. Roughly two-thirds of those covered in 2018 were parents, children and pregnant women, however this population accounted for only about 25 percent of Medicaid spending in 2018. Adults 65 or older and people with disabilities made up about 16 percent of the people served by these public insurance programs, yet they accounted for nearly 60 percent of spending.<sup>2</sup>

**Figure 1: Percentage of the population within the region enrolled in Medicaid**



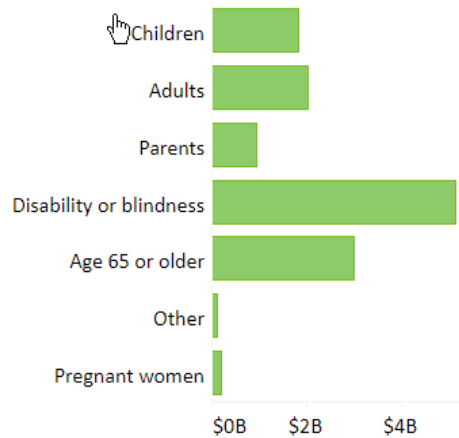
Source: [Minnesota Department of Human Services: Who Medicaid and MinnesotaCare Serve \(https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/\)](https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)

**Figure 2: Percentage of the population within the county enrolled in Medicaid**



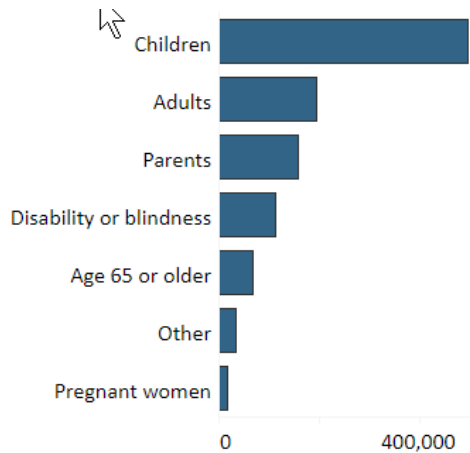
Source: [Minnesota Department of Human Services: Who Medicaid and MinnesotaCare Serve \(https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/\)](https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)

**Figure 3: Statewide total cost of care by eligibility type**



Source: [Minnesota Department of Human Services: Who Medicaid and MinnesotaCare Serve \(https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/\)](https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)

**Figure 4: Statewide enrollment by eligibility type**



Source: [Minnesota Department of Human Services: Who Medicaid and MinnesotaCare Serve \(https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/\)](https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)

**Medical Assistance enrollment is split nearly evenly between the seven-county metro area and Greater Minnesota.** However, Medical Assistance enrollment makes up a higher percentage of the total population in many Greater Minnesota counties compared to the metro area.<sup>3</sup>

**MinnesotaCare enrollment makes up a nearly equal percentage of the regional population in all six Minnesota regions.** Enrollment is split nearly evenly between the seven-county metro area and Greater Minnesota.<sup>3</sup>

Neither Medical Assistance nor MinnesotaCare include advance care planning or palliative care benefits. Seven states (Illinois, Minnesota, North Dakota, South Carolina, Utah, Virginia, and West Virginia) report that their State Employer Health Plans (SEHP) offer a palliative care benefit to members. The Minnesota State Employee Group Insurance Program defines available palliative care services and associated cost sharing with its members. Plans offer palliative care services, such as advance care planning, accompaniment to office visits, pediatric and adolescent anticipatory grief support counseling, home health aide and respite care services, and bereavement supports, when ordered in writing by a physician and included in the written home care plan. Palliative care services are available to most members at no cost, but palliative care is subject to the deductible for members enrolled in the program’s high-deductible plan.<sup>4</sup>

According to the National Academy for State Health Policy (NASHP), five percent of Medicaid beneficiaries account for more than 50 percent of the program’s expenditures. State policymakers are paying increased attention to better managing the health care needs of these individuals, many of whom have complex and serious illnesses, and some of whom are near the end of life. When providing quality care to patients with complex needs, curative treatment is often not enough: palliative care – addressing the physical, emotional, and spiritual needs of individuals with serious illness – can offer additional tools to states seeking to promote high-value care for populations with complex needs.<sup>5</sup>

Unlike hospice, which is often limited to those at the very end of life, palliative care can be delivered alongside curative treatment at any stage of a serious illness. Adding palliative care to treatment options has been shown to improve health outcomes and quality of life, while lowering costs for high-need, high-cost populations. One study of Medicaid enrollees diagnosed with serious illness and/or a history of hospitalization found that

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

palliative care contributed to an average savings of almost \$7,000 per person when compared to patients who did not receive palliative care.<sup>5</sup>

National Academy for State Health Policy also suggests that for specialty palliative care services, state Medicaid programs can identify patient populations that may benefit most from these services, to help increase access and target scarce resources. States can identify priority populations based on factors such as functionality, diagnosis, or level of acuity. California's Medicaid program, Medi-Cal, designed its palliative care benefit to address the needs of individuals with congestive heart failure, chronic obstructive pulmonary disease, advanced cancer, and liver disease. Use of claims and clinical data can assist states in identifying patients who could benefit most from palliative care services. States can also consider bolstering access to palliative care in settings that serve complex patients, such as post-acute rehabilitation and skilled nursing facilities.<sup>5</sup>

Minnesota patients receiving Medical Assistance or MinnesotaCare benefits represent some of the most vulnerable of Minnesota's population. As the pandemic worsens, and the state faces further restrictions, Minnesota's most vulnerable face additional stressors and need, now more than ever, for the essential supports that palliative care offers.

As COVID-19 continues to ravage the state, states can seek flexibility during emergencies using Section 1135 emergency waivers and Medicaid 1915(c) Appendix K waivers, making modifications to state 1115 demonstrations waivers, 1915(c) home and community-based services waivers, and Medicaid state plan amendments. The Centers for Medicare & Medicaid Services provide a 1135 waiver checklist to assist states. Within the checklist, flexibilities that could support remote palliative care services include<sup>5</sup>:

- Suspension of Medicaid fee-for-service prior authorization requirements
- Requiring fee-for-service providers to extend pre-existing authorizations through which a beneficiary has previously received prior authorization, through the termination of the emergency declaration
- Permitting providers located out-of-state or territory to provide care to an emergency state's Medicaid enrollee and be reimbursed for that service.

In order to provide palliative care benefits to those who need it most, the Council recommends the following for Minnesota Medical Assistance and MinnesotaCare:

**KEY RECOMMENDATION:** Enable Minnesota's Medical Assistance and MinnesotaCare to pay for high-value services such as palliative care and advance care planning to benefit those with serious illnesses or life-limiting conditions. Existing codes can be used, and suggested codes include but are not limited to:

- HCPCS S0527 End-of-life counseling
- CPT 99497, 99498 Advance Care Planning (discussion)
- CPT 99366, 99368 Inpatient / Outpatient Inter-disciplinary Care Team Consult

*Note: CPT 99341-99350 Home / Community (Inter-disciplinary) Care Team Consult is already offered with Minnesota's Medical Assistance program*

**KEY RECOMMENDATION:** Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

**KEY RECOMMENDATION:** Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.

**KEY RECOMMENDATION:** Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent and young adult, and perinatal.

**Recommendation:** Create a palliative care benefit in Medical Assistance and MinnesotaCare fee-for-service, or reimburse those codes used in palliative care.

**Recommendation:** Create a Medical Assistance and MinnesotaCare demonstration project that could eventually be scaled up to the whole state and/or the whole Medical Assistance population.

**Recommendation:** Require palliative care benefits to include telehealth options, in order to reduce health risks to and from medical clinics, and to ease transportation burdens on our most vulnerable patients and families.

**Recommendation:** Consider distributing Palliative Care information as part of or shortly after a patient's diagnosis of a serious illness or life-limiting condition, especially for patients with high needs or complex diagnosis providing that essential support to the patient and their families.

---

<sup>1</sup> [Medical Assistance and MinnesotaCare \(www.mnsure.org/shop-compare/financial-help/ma-mncare/index.jsp\)](http://www.mnsure.org/shop-compare/financial-help/ma-mncare/index.jsp)

<sup>2</sup> [Who Medicaid and MinnesotaCare Serve \(https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/\)](https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)

<sup>3</sup> [Who Medicaid and MinnesotaCare Serve \(https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/\)](https://mn.gov/dhs/medicaid-matters/who-medicaid-and-minnesotacare-serves/)

<sup>4</sup> [Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs \(PDF\) \(https://www.nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf\)](https://www.nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf)

<sup>5</sup> [Building Infrastructure and Promoting Quality \(https://www.nashp.org/palliative-care/building-infrastructure-and-promoting-quality/\)](https://www.nashp.org/palliative-care/building-infrastructure-and-promoting-quality/)

## Palliative Care and Serious Illness During the Pandemic

In August 2020, The Minnesota Palliative Care Advisory Council participated in the Serious Illness Action Network convened by Minnesota Network of Hospice & Palliative Care and Stratis Health. Over 100 stakeholders, including patients and families, caregivers, clinicians, health care organization leaders and staff, payers, and allied organizations, gathered to discuss, “Addressing Urgent Needs During the Pandemic.” This virtual forum included presentations on telehealth, Provider Orders for Life Sustaining Treatment (POLST), advance care planning, hospital-at-home, and long-term care.

Participants provided their input and recommendations through online platforms during and after the forum. Stratis Health and MNHPC leaders synthesized the input and discussion into actionable recommendations organized around three themes:

### **KEY RECOMMENDATIONS: Technology and Infrastructure**

- Rethink how technology can support those with serious illness care
- Develop a registry for provider orders for life-sustaining treatment (POLST) and advance care planning (ACP) documentation
- Improve access to and support for the use of technology for patients and caregivers

### **KEY RECOMMENDATIONS: Workforce and Training Support**

- Normalize and proactively support ACP as part of health care delivery
- Support workforce development and confidence in technology use for remote care delivery

### **KEY RECOMMENDATIONS: Regulation and Reimbursement**

- Reduce variations in coverage and payment requirements across payers that make it challenging to develop and deliver serious illness care
- Provide adequate reimbursement and regulatory incentives for increasing utilization of ACP
- Implement regulatory and reimbursement flexibilities to structure services that better meet the needs of seriously ill patients

The Council supports the recommendations produced during the Serious Illness Virtual Action Network meeting.

Access the full report: [Minnesota Serious Illness Action Network: Addressing Urgent Needs During the Pandemic \(PDF\)](#).

## Palliative Care and Health Equities

An extraordinary year for our country and our state has heightened the Council's awareness and commitment to better understand and respond to the fear, suffering, systemic discrimination, and exclusions of Black, Indigenous, and People of Color (BIPOC) in Minnesota. In the context of palliative care, the Council will focus on recommendations to right these wrongs, recognizing that they impact every area of human services, including healthcare.

We, as the Council, commit to health equity, and to equitable access to health care. The Coronavirus pandemic has laid bare these inequities through its disproportionate impacts on those who are vulnerable and marginalized in our state, our BIPOC neighbors. In Minnesota, Black and Hispanic individuals are one and half times more likely to get COVID-19; twice as likely to be hospitalized; and more than twice as likely to be admitted to the ICU. Minnesota's Indigenous peoples, if they even have access to adequate facilities, have staggering death rates for their population.

The Minnesota Department of Health publishes cumulative COVID statistics by race and ethnicity<sup>1</sup> for the Minnesota. Statistics for Black, Asian, Hispanic, and Indigenous cultures, representing 20% of the state's population, get lost when the statistics for All Cases, Hospitalizations, ICU Hospitalizations, and Deaths include the White population, which is 80% of Minnesotans.<sup>1</sup>

---

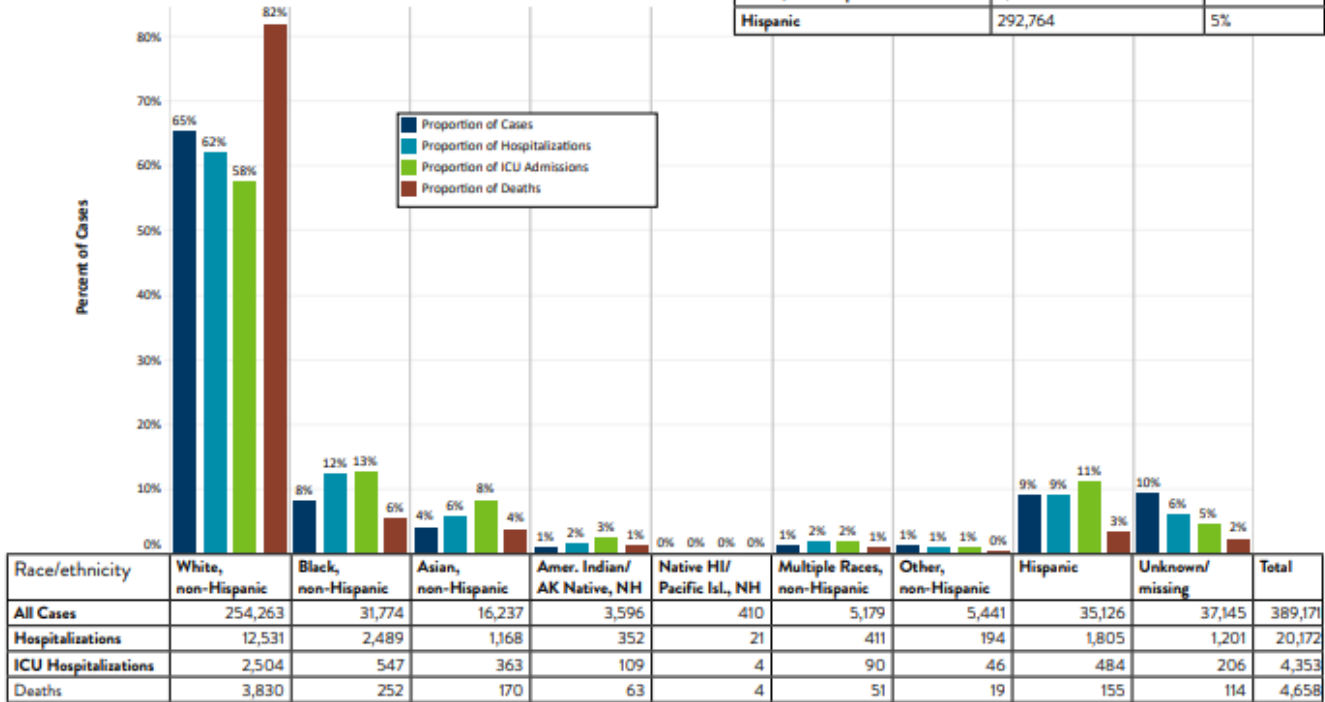
<sup>1</sup> [Minnesota Department of Health Weekly COVID-19 Report 12/17/2020 \(PDF\)](https://www.health.state.mn.us/diseases/coronavirus/stats/covidweekly51.pdf)  
(<https://www.health.state.mn.us/diseases/coronavirus/stats/covidweekly51.pdf>)

Figure 5: Minnesota COVID-19 Cases by Race / Ethnicity

## Demographics: Race & Ethnicity

Race and ethnicity for confirmed and probable cases. Race and ethnicity is reported during case interview. Individuals who report more than one race are categorized into the multiple race category.

Race/Ethnicity	Minnesota Population (2018)	% of Population
White, non-Hispanic	4,438,071	80%
Black, non-Hispanic	336,505	6%
Asian, non-Hispanic	260,797	5%
American Indian/Alaska Native, non-Hispanic	53,168	1%
Native Hawaiian/Pacific Islander, non-Hispanic	1,799	<1%
Multiple Races, non-Hispanic	137,233	2%
Other, non-Hispanic	7,021	<1%
Hispanic	292,764	5%



Source: [Minnesota Department of Health Weekly COVID-19 Report 12/17/2020 \(PDF\)](https://www.health.state.mn.us/diseases/coronavirus/stats/covidweekly51.pdf)  
<https://www.health.state.mn.us/diseases/coronavirus/stats/covidweekly51.pdf>

It's when we use the same data but change the lens to focus on each culture as a whole, reporting their statistics as a percent of their Minnesota population, that the impacts of COVID-19 on those already suffering the effects of health disparities become visually startling:



**Figure 6: MDH 12/24/2020 Black Population**

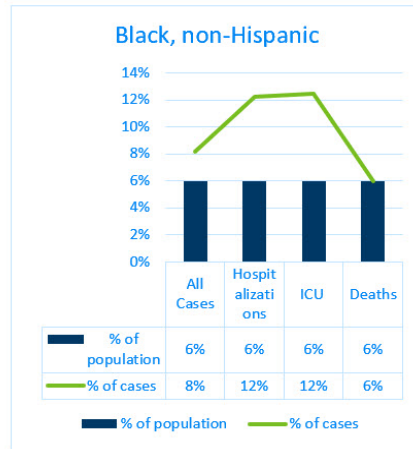


Figure 6 shows that while Black Minnesotans make up 6% of the state’s population, they are 8% of all COVID-19 cases, 12 % of all hospitalizations, 12% of all ICU admittances, and 6% of all deaths

**Figure 7: MDH 12/24/2020 Hispanic Population**

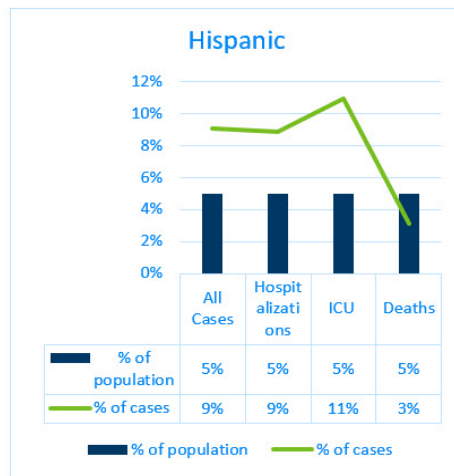


Figure 7 shows that while Hispanic Minnesotans make up 5% of the state’s population, they are 9% of all COVID-19 cases, 9% of all hospitalizations, 11% of all ICU admittances, and 3% of all deaths.

**Figure 8: MDH 12/24/2020 Asian Population**

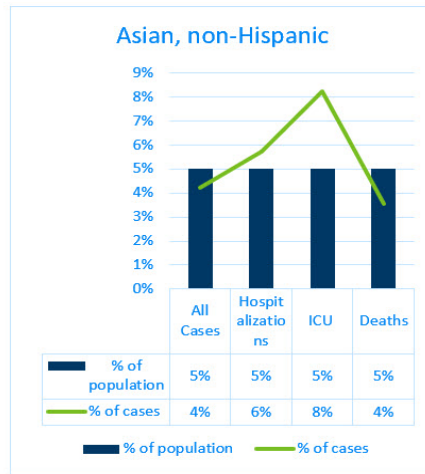


Figure 8 shows that while Black Minnesotans make up 5% of the state’s population, they are 4% of all COVID-19 cases, 6% of all hospitalizations, 8% of all ICU admittances, and 4% of all deaths.

**Figure 9: MDH 12/24/2020 Native HI Population**

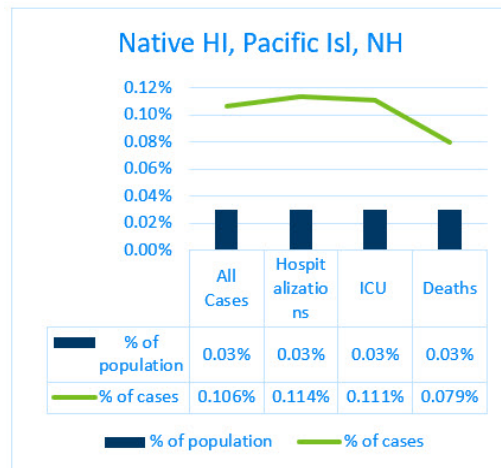


Figure 9 shows that while Native Hawaiian Minnesotans make up 0.03% of the state’s population, they are 0.106% of all COVID-19 cases, 0.114% of all hospitalizations, 10.111% of all ICU admittances, and .079% of all deaths.

**Figure 10: MDH 12/24/2020 American Indian Population**

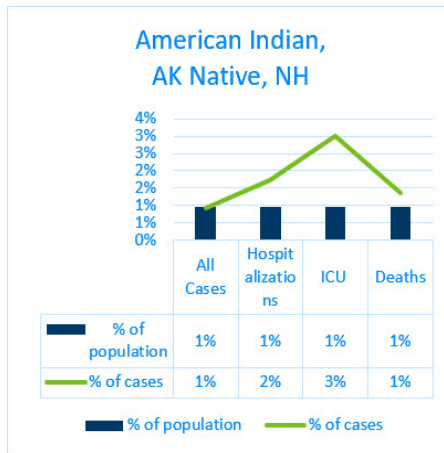


Figure 10 shows that while American Indian Minnesotans make up 1% of the state’s population, they are 1% of all COVID-19 cases, 2% of all hospitalizations, 3% of all ICU admittances, and 1% of all deaths.

**Figure 11: MDH 12/24/2020 White Population**

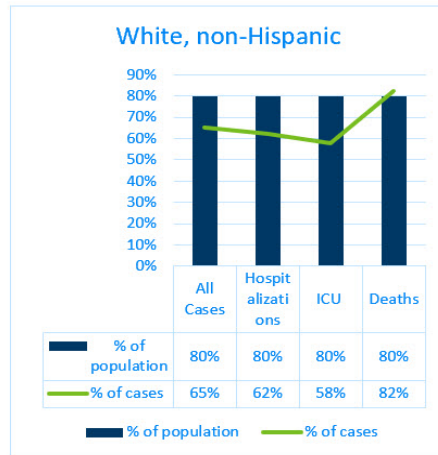


Figure 11 shows that while white Minnesotans make up 80% of the state’s population, they are only 65% of all COVID-19 cases, 62% of all hospitalizations, 58% of all ICU admittances, and 82% of all deaths.

It would be simple to say that we need change to reduce suffering - and that palliative care is the obvious solution. But while palliative care is an essential element of comprehensive care, it cannot be the band-aid on the current system of care. COVID has made this clear to us: patients are suffering physical, emotional, mental, and spiritual pain and distress. “I can’t breathe” is heard from patients slowly suffocating as their lungs are no longer able to function. “I don’t want to die alone,” from patients alone in their room, family and friends unable to visit them. “I want a song or a prayer,” from patients looking for the comfort of normal everyday rituals.

Yet there has been no obvious discussion of the criteria for adequate palliative care for people suffering and dying of COVID. And given the disproportionate sickness and death in BIPOC communities, as well as lack of

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

access to hospital and ICU care, these people, our neighbors, are suffering the most without help. While the Council's ultimate goal is "palliative care for all," we need to make health equity the core of all we do. Therefore, justice, equity, diversity and the lens of inclusion must frame inclusive spaces for everyone - especially in healthcare for all of those who are seriously ill.

The Council will include a deeper investment in palliative care equity over the remaining years through several methods: individually understanding our involvement with supporting structures of systemic racism and bringing our group insights forward. We will also engage our communities, work with more inclusive methods, and frame our recommendations to meet the needs of **all** people living in Minnesota. May our state be a model to other state palliative care initiatives in our nation!

We have compiled a growing list of required reading resources for all council members on identifying and responding to systemic racism (See appendix). We will spend a portion of each council meeting reviewing a required reading and processing as a group what we have learned, and how it can be applied to what we are working on - both as a council and in our daily activities in the coalitions we belong to.

We must dedicate our time to find equitable ways to contribute to healing of all patients - starting with healing injustices in our system. We have started simply, essentially assuming we don't know what people need, but by looking inward we can be more effective when we begin asking our communities what is needed next. By listening we can transform.

In closing, we are motivated by the words of Rev. Dr. Martin Luther King, Jr. said in his 1967 speech, "The Other America,":

*"Let me say as I've always said, and I will always continue to say, that riots are socially destructive and self-defeating . . . But in the final analysis, **a riot is the language of the unheard.** And what is it that America has failed to hear? It has failed to hear ... the plight of the ... poor has worsened over the last few years. It has failed to hear that the promises of freedom and justice have not been met. And it has failed to hear that large segments of white society are more concerned about tranquility and the status quo than about justice, equality and humanity."*

### **RECOMMENDATIONS:**

The Council supports the recommendations created by 30 leading health care organizations released on December 21, 2020.<sup>1</sup> A partial list is shown below:

- Re-examine health care organizational policies with an equity lens and make any policy changes needed to promote equity and opportunity.
- Seek to understand different perspectives, experiences and appropriately adapt our behaviors to improve culturally responsive care.
- Work to eliminate decisions that negatively impact underrepresented and underserved groups.
- Improve access to and consumer experience for all needed care services- primary, specialty care, and hospital care.
- Partner with policymakers, employers, and community advocates to remove the economic barriers to health equity.

MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

- Continue to build pathways that support our patients in addressing their health-related social needs and provide connections to community resources.
- Renew and expand our organizations' commitment to providing anti-racism and implicit bias training for all leaders and staff.
- Advocate for increased funding for social needs, social services and programs that promote social justice.

---

<sup>1</sup> [Minnesota health care leaders working together on COVID-19 response, ending systemic racism \(https://kstp.com/news/minnesota-health-care-leaders-working-together-on-covid-19-response-ending-systemic-racism-december-21-2020/5957754/\)](https://kstp.com/news/minnesota-health-care-leaders-working-together-on-covid-19-response-ending-systemic-racism-december-21-2020/5957754/)

## Palliative Care and the Transportation Divide

The current pandemic continues to demonstrate what Minnesota’s most vulnerable residents, the elderly, infirm, low-income or no-income, have long known: transportation is a social determinant of health. Where you live matters, especially for palliative care availability and accessibility.

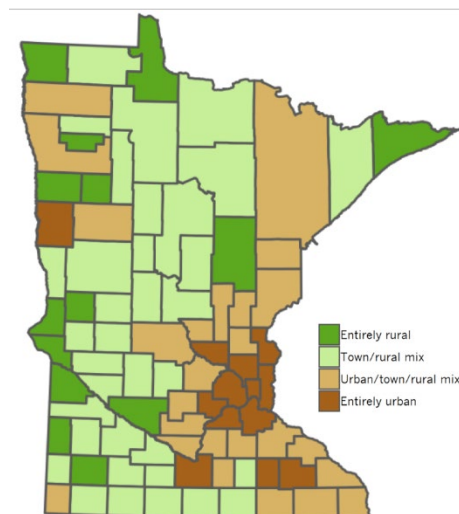
The United State Department of Agriculture Economic Research Service developed the Rural-Urban Commuting Area codes as a way to define geographic areas using more than population alone. These codes incorporate population density, urbanization, and daily commuting to define a geographic area.<sup>1</sup>

This classification is reflected in the map below and can be summarized as follows:

- 14 counties, or 16%, are considered entirely rural.
- 35 counties, or 40%, are considered mixed town / rural.
- 25 counties, or 29%, are considered mixed urban / town / rural.
- 13 counties, or 15%, are considered entirely urban.

*(definitions for RUCA classifications found in Appendix E)*

**Figure 12: County categories for rural-urban commuting**



Source: <https://www.ruralmn.org/wp-content/uploads/2019/02/ruca-county-map.png>

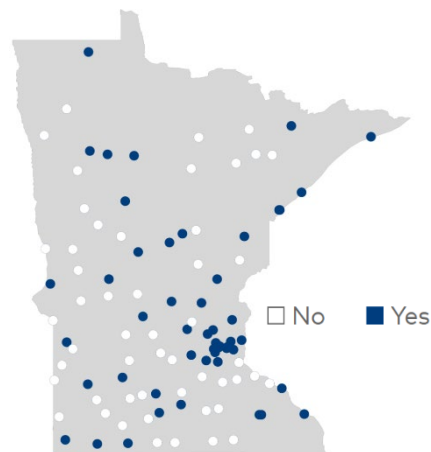
When a patient is eligible to receive, or is receiving palliative care, that means the patient is living with one or more serious illnesses, life-limiting conditions, or life-threatening conditions, all of which affect the patient’s mobility. At best, the effect on the patient’s mobility is temporary, limited to the time the patient is receiving treatment and their recovery period. At worst, the effect is permanent, making travel to and from clinics and hospitals difficult for the patient, ultimately increasing the patient’s reliance on others for transportation for essentials and medical care.

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

In the map provided by the Center to Advance Palliative Care (Figure 13 below), locations of Minnesota's hospitals are shown by either a white dot or a blue dot:

- Blue dots reflect hospitals providing palliative care.
- White dots reflect hospitals not providing palliative care.

**Figure 13: Hospital Palliative Care**



Source: <https://reportcard.capc.org/wp-content/uploads/2020/02/Minnesota-state-map.png>

With some exceptions, those hospitals providing palliative care (the blue dots), primarily fall within counties that are classified as entirely urban or a mixture of urban / town / rural, subtly making Palliative Care an urban or town benefit. While there are 17 programs that provide palliative care within a community's local health care system, they are not reflected on this map.<sup>2</sup>

Those living in rural areas face unique challenges related to transportation, including distance to health care and other services, the impact of adverse weather on travel conditions, and limited availability of public and private transportation services. Rural residents cannot receive health care services without transportation to access facilities and providers. Beyond direct access to care, transportation is essential for accessing basic necessities for health and wellness, such as food, recreation, employment, education, and social support.<sup>3</sup>

Medicaid is currently an important source of transportation for individuals who qualify, providing emergency and non-emergency medical transportation. However, exact benefits vary by state, and the Centers for Medicare & Medicaid Services only permit reimbursement for "loaded" miles in which the beneficiary is in the vehicle. This puts rural transportation providers at a distinct disadvantage, since they need to bear the burden of driving more unreimbursed miles to pick up a passenger.<sup>4</sup>

Despite the importance of travel and mobility, transportation services are seriously lacking in many rural areas. Nearly four percent of rural households — almost two million rural residents — do not have access to a car; rural areas are also much less likely to have access to public transportation services. Provision of transportation services varies by state and locality, and policies (such as the aforementioned "loaded miles" policy) may act as a disincentive for transportation providers to enter the market. The National Rural Health Association cited transportation as a key policy concern for older adults' well-being in their 2014 legislative agenda, but research is lacking on specific rural transportation challenges and potential policy solutions.<sup>4</sup>

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

Given the challenges for physical transportation identified in this section, it would be easy to assume that telehealth options would be a practical solution. However, as you will read in the next section, Palliative Care and the Digital Divide, telehealth alone cannot provide an adequate solution for the geographically-challenged in need of palliative care.

**RECOMMENDATION:** Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the “loaded miles” benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services. This will reduce financial burdens placed on caregivers providing transportation.

**RECOMMENDATION:** The Council recommends the legislature request research on rural transportation challenges affecting access to timely, appropriate health care, especially serious illness care.

**RECOMMENDATION:** The Council recommends that the legislature request research on palliative care availability (in medical facilities and community-based) throughout rural Minnesota, so that the Council can identify potential policy solutions.

---

<sup>1</sup> [County categories for rural-urban commuting areas map \(https://www.ruralmn.org/rural-urban-commuting-areas-explanation-of-county-categories/ruca-county-map/\)](https://www.ruralmn.org/rural-urban-commuting-areas-explanation-of-county-categories/ruca-county-map/)

<sup>2</sup> [Minnesota: Palliative Care in Your State \(https://reportcard.capc.org/state/minnesota/\)](https://reportcard.capc.org/state/minnesota/)

<sup>3</sup> [Paving the Way: Addressing Transportation as a Social Determinant of Health for Rural Residents \(https://rhrc.umn.edu/project/paving-the-way-addressing-transportation-as-a-social-determinant-of-health-for-rural-residents/\)](https://rhrc.umn.edu/project/paving-the-way-addressing-transportation-as-a-social-determinant-of-health-for-rural-residents/)

<sup>4</sup> [Rural Transportation: Challenges and Opportunities \(https://rhrc.umn.edu/publication/rural-transportation-challenges-and-opportunities/\)](https://rhrc.umn.edu/publication/rural-transportation-challenges-and-opportunities/)



## Palliative Care and the Digital Divide

Telehealth affords an opportunity to reduce, yet not entirely eliminate, the healthcare access problems due to transportation barriers. While eliminating some physical transportation barriers to palliative care, it harbors its own unique barriers to effective provider/patient interactions. These barriers need to be addressed to realize the full potential of telehealth.

What the state has learned about effective distance learning during COVID can also be applied to telehealth. Both require:

- **Accessibility:** access to a stable internet connection.
- **Equipment:** equipment to access the internet (e.g., a computer, laptop, or phone).
- **Affordability:** affordable equipment and internet service consistent with other essential household needs like housing, food, and transportation.
- **Technical skills and support:** skills to set up and use the internet connection and equipment, and to troubleshoot problems.
- **Cognitive and physical ability:** to use the connection and equipment.
- **Privacy:** the need for a private or quiet setting within the household.

According to BROADBANDNOW, **89.6% of Minnesota has access to terrestrial broadband**. Unfortunately, only **15.9% of Minnesotans have access to a low-cost plan**, defined as less than \$60 per month,<sup>1</sup> and does not include the cost of equipment required to access the internet.

Technical skill, or technical support is required to create the at-home infrastructure required for telehealth to work (e.g., wired or wi-fi internet connections, equipment, accounts, and passwords). It is also an essential requirement to troubleshoot and correct infrastructure problems.

Telehealth may also require a caregiver to be present during the call, especially if the patient has cognitive impairment, such as Alzheimer's, or lacks the physical ability to use a computer or phone due to physical challenges, such as poor vision or hearing, rheumatoid arthritis or declining health.

There is also the need for privacy within the patient's home. If the patient is unable to find or move to a private setting, they may be unwilling to discuss all of their concerns during a telehealth visit.

While telehealth does reduce some transportation challenges it also brings its own technological challenges. And once again Minnesota's most vulnerable populations, the elderly, infirm, low-income or no-income, and rural are potentially impacted by the shift to telehealth.

### RECOMMENDATIONS:

The Council supports the recommendations created by 30 leading health care organizations released on December 21, 2020<sup>2</sup>, in particular, those recommendations that support equitable access to health care by removing those economic barriers that impede a patient's ability to access telehealth:

- Work to eliminate decisions that negatively impact underrepresented and underserved groups.

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

- Improve access to and consumer experience for all needed care services- primary, specialty care, and hospital care.
- Partner with policymakers, employers, and community advocates to remove the economic barriers to health equity.
- Continue to build pathways that support our patients in addressing their health-related social needs and provide connections to community resources.

---

<sup>1</sup> [Internet Access in Minnesota: https://broadbandnow.com/Minnesota](https://broadbandnow.com/Minnesota)

<sup>2</sup> [Minnesota health care leaders working together on COVID-19 response, ending systemic racism \(https://kstp.com/news/minnesota-health-care-leaders-working-together-on-covid-19-response-ending-systemic-racism-december-21-2020/5957754/\)](https://kstp.com/news/minnesota-health-care-leaders-working-together-on-covid-19-response-ending-systemic-racism-december-21-2020/5957754/)

## Palliative Care and Reimbursement

Joe was 62 with advanced heart failure. He was able to get out of the house on his own but had frequent episodes of rapid weight gain from fluid retention, breathlessness and weakness, which brought him to the emergency department of his local hospital. He often forgot to reorder his medications. He was reluctant to go to his primary care provider because the copayments were too expensive. He was not ready for hospice, but unable to keep healthy at home. Because he was not homebound, he was not eligible for home care nursing. The cost of his care was mounting, his quality of life was poor, and he was not getting the ongoing care he needed.

Situations like this are too common. The absence of effective symptom management adversely affects the person's quality of life, contributes to fractured and lower quality health care, and is not cost effective.

Minnesota legislators should consider ways for people with serious illness to receive palliative care services at the time and place that is right for them and fiscally responsible. While striving for the triple aim of health care there is a great need to develop a sustainable financial model to accomplish this. This includes ongoing discussions of both benefit design and reimbursement options in order to provide good care in a fiscally responsible way within the limited resources of the state health care budget.

A research study completed and published in the Journal of Palliative Medicine titled "The impact of home-based palliative care in an accountable care organization," by Lustbader et al (2017) reported the following results:

- Cost per patient in final 3 months of life was \$12,000 lower than usual care (\$20,420 vs \$32,420 for usual care)
- Hospital admissions were reduced by 34%
- Hospice enrollment was increased by 35%
- Median hospice length of stay increased 240% compared to usual care (34 days vs 10 days), as did length of time in hospice

Several states have legislated health insurance benefit design and reimbursement structures for palliative care. These models vary considerably based on the states' individual priorities and needs but have shown cost savings and improved patient satisfaction.

Some states, for example, have built Medicaid programs that require coverage of certain service codes – such as end of life counseling, advanced care planning, interdisciplinary team consultations, or in-home counseling. States have also chosen to develop clear eligibility criteria for these services by articulating types of medical situations that might qualify someone for palliative care services.

Payment models for palliative care can vary and are sometimes addressed in state legislation. Historically, a fee-for-service model has been used, where each individual service or interaction generates a medical bill. Other models have used care management fees or monthly case rates, especially for patients with serious illnesses. Options might also include integrating a palliative care plan into the medical home model or into an ACO (accountable care organization) structure. Palliative care improves individuals' quality of life, brings value to the health of our communities, and typically lessens the overall cost of health care for patients receiving it. Designing reimbursement to support these palliative care resources is needed.

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

Eliminating cost sharing for the patient related to advance care planning services is a strategy that should be considered. Advance care planning services help patients and families understand and articulate their care goals, including whether and when they want to stop life-sustaining medical interventions. We know that many patients each year receive medical treatments towards the end of life that they never wished to have – but without planning those wishes are not always known. When health care providers partner with patients in this planning, informed decisions are made and communicated much more effectively.

Advance care planning visits, when done at their best, often need dedicated time to focus on that topic. This might not be part of a physician visit, and it commonly includes family members joining both in person and remotely. Provider reimbursement for this service is important but getting patients to take their time to have these discussions is also a challenge. One option that may help is to eliminate patient cost sharing in the form of copays and deductibles for this service, and to do so for all patients and not just those already facing serious illness.

Our current coronavirus pandemic has challenged the delivery of health care in many ways. With that challenge, though, has come opportunities to innovate and test new ways of caring for people in our communities. There is both a need and opportunity now to do the same regarding palliative care. This is the time to look differently at palliative care models -- at where that care can be delivered, at who can be a part of that care delivery, and at what reimbursement and benefits might look like.

Palliative care and end of life care often include hospitalizations. Some of these hospitalizations can be avoided with palliative care as shown in this figure below, broken down by common diagnoses. In Figure 14, the blue bar shows the cost of hospitalizations when a palliative care program is involved. The gold bar shows the costs of hospitalization for those who had usual care without palliative care involved.

**Figure 14: Palliative Care Program Hospital Costs**

**Palliative Care Program Hospital Costs per Month and Satisfaction Score**

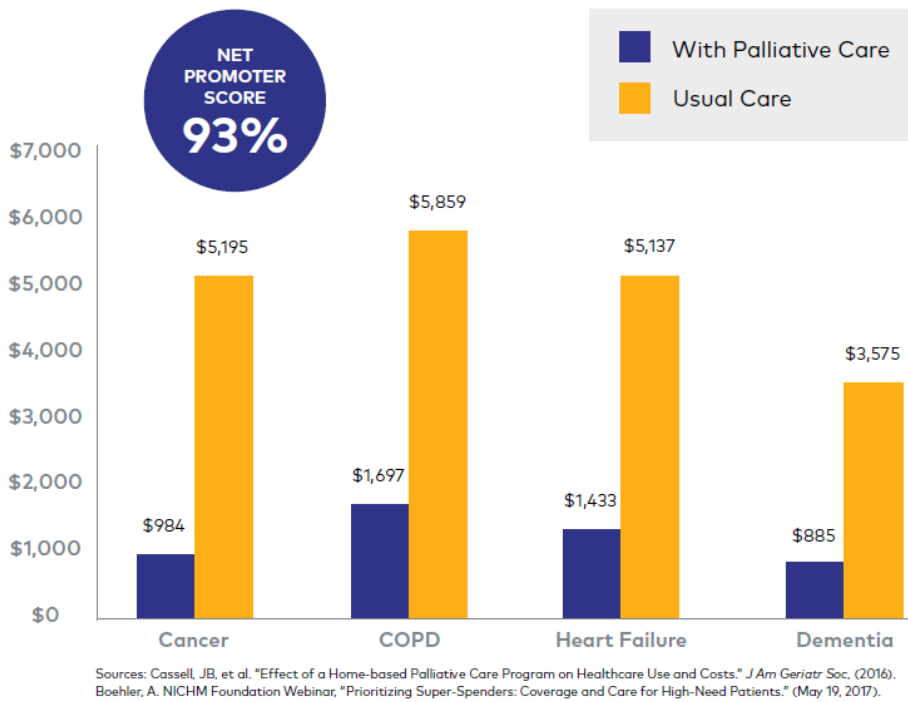
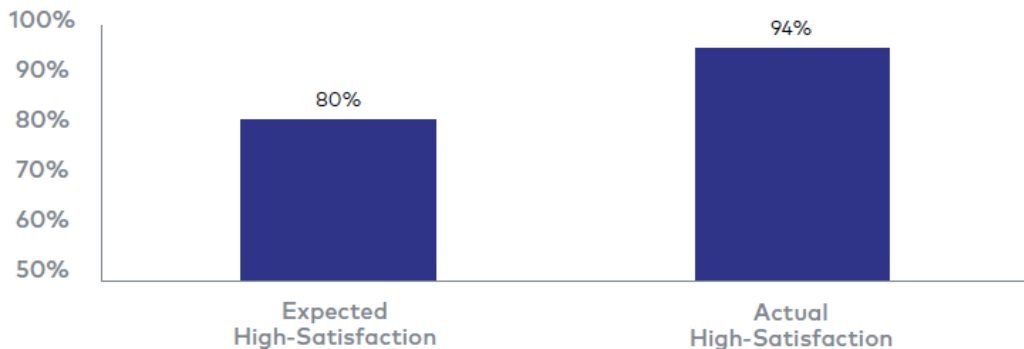


Figure 15 shows patient satisfaction with palliative care. The first bar is what the patient expected (80%) and the second bar (94%) shows how satisfaction with palliative care exceeded expectations.

**Figure 15: Regence BlueCross BlueShield Personalized Care Support Program's Satisfaction Results**



The final chart shows savings generated by Palliative Care by care setting.

**Figure 16. Savings Generated by Palliative Care by Care Setting**

Setting	Results	Studies
Inpatient Hospital	\$1,696 costs saved per admission	Morrison, 2008
	43% lower ICU admissions	Gade, 2008
	1.1 day length of stay reduction (oncology)	May, 2017
	Automatic palliative care consultation reduced re-admissions by 48%	Adelson, 2017
Outpatient	In Primary Care: 20% fewer hospital admissions	RTI International, 2006
	In Cancer Center: 50% reduction in hospitalization, with 35% reduction in ED visits	Scibetter, 2015
Skilled Nursing Facility	43% reduction in case transitions (to ED or hospital)	Miller, 2016
Home-Based	36% lower cost (\$12,000 saved per patient)	Lustbader, 2016
	48% to 56% reduction in hospital admissions	Cassel, 2016
Pediatric (Cross-Setting)	\$3,331 saved PMPM, including a 45% reduction in average patient days	Gans, 2016

\*A good resource for cost and utilization results that has been used successfully by actuaries: Smith, Susan, et al. “Evident on the Cost and Cost-Effectiveness of Palliative Care: A Literature Review” *J Palliat Med* (2014).

**REIMBURSEMENT RECOMMENDATIONS:**

**RECOMMENDATION:** Reduce variations in coverage and payment requirements across payers that make it challenging to develop and deliver serious illness care

**RECOMMENDATION:** Provide adequate reimbursement and regulatory incentives for increasing utilization of ACP

**RECOMMENDATION:** Implement regulatory and reimbursement flexibilities to structure services that better meet the needs of seriously ill patients

## Conclusion

As 2020 ends (finally!), the Palliative Care Advisory Council is reminded that these three legislative assignments constitute our core focus:

- An assessment of the availability of palliative care in the State of Minnesota.
- Analysis of barriers to greater access to palliative care.
- Recommendations for legislative action, with draft legislation to implement the recommendations.

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

We have not forgotten the nineteen recommendations from our 2020 report, nor have we forgotten the five prioritized recommendations from our retreat in February 2020.

We, like the rest of the state, shifted our focus during 2020 from the important to the critical and urgent, as identified by the pandemic and the summer's unrest. As professionals, and individuals, we became hyperaware of what the data was telling us: while all of the state's population experienced the pandemic, twenty percent of the state's population, the Black, Brown, Asian, and Indigenous, were disproportionately severely impacted compared to the remaining eighty percent, the White population.

2020 was a year that was 'in your face' as the difference between equality and equity, reflected in the state's COVID demographic data on race and ethnicity, was reported week after week.

Equality in medical treatments ensures every Minnesotan has access to care. Equity in medical treatments, however, ensures a person's care is based on their physical care needs as well as their social and cultural needs.

As a Council we recognize now more than ever, we need state specific research on the barriers to palliative care and a thoughtful policy response to address those barriers, ensuring equitable coverage and treatment for Minnesota's most vulnerable.

We need to study and learn how to factor in health disparities in order to arrive at truly equal and equitable approaches to addressing healthcare needs.

The Council recognizes that without appropriate funding for qualified researchers, we cannot effectively conduct a state level thorough assessment of the availability of palliative care within Minnesota, or determine how known barriers including income, jobs, transportation, and digital divides, impact our most vulnerable.

We are grateful for the collaboration and partnerships with national organizations such as Center to Advance Palliative Care (CAPC), National Coalition for Hospice and Palliative Care (NCHPC), Center to Transform Advanced Care (C-TAC), and the National Academy for State Health Policy (NASHP) for their continued sharing of national trends, and state trends when state level information is available.

The Council is also grateful for the support, collaboration, and partnerships with the Serious Illness Action Network, the Minnesota Network of Hospice & Palliative Care (MNHPC), Stratis Health, Honoring Choices Minnesota, and the American Cancer Society Cancer Action Network. Their information sharing is valuable and appreciated.

The Council hopes that as university and professional organizations develop research studies in the coming months, those organizations will reach out to Council members for input into these valuable research projects and analytics.

In closing, the Council thanks Commissioner Malcolm for her unwavering support and transparency of the data to all Minnesotans during this pandemic. Commissioner Malcolm, like many Minnesotans, endured the pain and suffering caused by the pandemic.

The Council, like the rest of the state, hopes that 2021 will be a better year.

Or stated in Latin, *MMXXI: potest esse melius annos singulos!*

## Appendix A: Summary of 2021 Key Recommendations

Each section in the report has specific recommendations for that topic. There are many. This summary does not include all the identified recommendations but rather identifies the few key recommendations for 2021 as follows:

1. Consider revising the language in 144.75A Subdivision 12 to eliminate the exclusive association of palliative care with hospice care.
2. Adopt the suggested definition of Palliative Care for Minnesota. (*See Definition Section for suggested language.*)
3. Enable Minnesota’s Medical Assistance and MinnesotaCare to pay for high-value services such as palliative care and advance care planning to benefit those with serious illnesses or life-limiting conditions using existing CPT or HCPCS codes.
4. Explicitly incorporate palliative care into existing Medical Assistance and MinnesotaCare waiver programs that focus on high need patients.
5. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the “loaded miles” benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
6. Consider making palliative care coverage a requirement for all Medical Assistance and MinnesotaCare managed care contracts in the next contracting cycle.
7. Consider adding palliative care coverage requirements in all settings to Medical Assistance and MinnesotaCare managed care organization contracts, including special considerations for pediatrics, adolescent and young adult, and perinatal.
8. Rethink how technology can support those with serious illness care.
9. Develop a registry for physician orders for life-sustaining treatment (POLST) and advance care planning (ACP) documentation.
10. Improve access to and support for the use of technology for patients and caregivers.
11. Normalize and proactively support ACP as part of health care delivery.
12. Support workforce development and confidence in technology use for remote care delivery.
13. Reduce variations in coverage and payment requirements across payers that make it challenging to develop and deliver serious illness care.
14. Provide adequate reimbursement and regulatory incentives for increasing utilization of ACP.
15. Implement regulatory and reimbursement flexibilities to structure services that better meet the needs of seriously ill patients.
16. Improve access to and consumer experience for all needed care service – primary, specialty care, and hospital care. (see the Health Equity Section for a list.)
17. Consider options with the Medical Assistance and MinnesotaCare plans to remove or offset the “loaded miles” benefit restriction that currently exists in benefits authorized by Centers for Medicare & Medicaid Services in order to reduce the financial burden on caregivers providing transportation.
18. Request research on rural transportation challenges affecting access to timely, appropriate health care (including palliative care).



## Appendix B: The Council's 2020 Recommendations

During 2019 the Palliative Care Advisory Council identified the following 19 recommendations to improve and strengthen Palliative Care within Minnesota. These 19 recommendations remain a priority for the Council. Recommendations are not listed in priority order.

1. Establish a clear definition for palliative care in state statute and relevant regulations, independent of hospice regulations.
2. Fund a statewide public education campaign around serious illness.
3. Fund a statewide public education campaign around end-of-life care.
4. Require a minimum number of hours of instruction in primary palliative care and pain management through state health professional licensure and continuing education guidelines for those who have Minnesota state licensure (Physician, Advanced Practice Provider, Registered Nurse).
5. Fund efforts to train professionals in primary palliative care.
6. Fund efforts to train professionals in specialty palliative care.
7. Support innovative certification opportunities for mid-career providers who want to focus in palliative care including tele-education and mentorship programs.
8. Establish or expand reimbursement programs for training in specialty palliative care for all core interdisciplinary team members (Physician, Advanced Practice Provider, Registered Nurse, Social Worker, Chaplain, Child Life Specialist).
9. Require nursing schools to include minimum standards for primary palliative care education for all nursing students.
10. Require medical schools to include minimum standards for primary palliative care education for all medical students.
11. Require physician residencies to include minimum standards for primary palliative care education for all residents.
12. Require more advanced palliative care education and skills in key physician fellowships including but not limited to oncology, radiation oncology, cardiology, geriatrics, neonatology, critical care/pulmonology, nephrology, and surgical specialties such as neurosurgery, cardiothoracic surgery, and trauma surgery.
13. Ensure that palliative care benefits offered by private and public payers are comprehensive and support the full interdisciplinary team.
14. Expand access to home-based palliative care.
15. Expand access to pediatric palliative care in all settings to reduce the gap in services.
16. Establish a state-wide interdisciplinary palliative care research center or hub.
17. Require state regulatory agencies to develop measures, collect data, and report on palliative care access and quality. Measures should include disparities in access and utilization of palliative care across populations, care settings, and geography.
18. Encourage Minnesota based palliative care programs to participate in currently established national data collection efforts such as the Center to Advance Palliative Care National Palliative Care Registry.
19. Establish minimum standards for what constitutes a palliative care program with attention to challenges faced by different types of providers.

## Appendix C: Medicaid Reimbursement by State

Medicaid Reimbursement for Select Palliative Care-Related Current Procedural Terminology (CPT) and Healthcare Common Procedure Coding System (HCPCS) Codes<sup>2</sup>

State	Medicaid Reimbursement (for one or more Medicaid populations)					
	End-of-Life Counseling HCPCS (S0257)	Advanced Care Planning CPT (99497, 99498)	Home/Community Inter-disciplinary Care Team Consult CPT (99341-99350)	Inpatient/Outpatient Inter-disciplinary Care Team Consult CPT (99366, 99368)	Individual, Family, Marriage Counseling, In-Home CPT (99510)	Respite, In-Home HCPCS (T1005)
AL			✓			
AZ	✓	✓				
CA	✓	✓	✓	✓		✓
CO		✓ (99497 only)	✓	✓		✓
CT			✓			
DE	✓	✓	✓	✓	✓	✓
DC			✓	✓		✓
FL			✓			
GA			(99341, 99342, 99343 only)			
HI			✓	✓		
ID		✓	✓	✓		
IL			✓			
IN			✓			✓
IA		✓	✓		✓	✓
LA			✓			
ME			✓			✓
MD			✓			
MA		✓	✓	✓		
MI		✓	✓			
MN			✓		✓	✓
MO			✓	(99366 only)		
MT		✓	✓			
NE		✓	✓			
NV			✓			
NH		✓	✓	✓		✓
NJ			(99347, 99348)	✓		✓

<sup>2</sup> [Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs Appendix B \(PDF\) \(https://www.nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf\)](https://www.nashp.org/wp-content/uploads/2018/12/Palliative-Care-Brief-Final.pdf)

MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

State	Medicaid Reimbursement (for one or more Medicaid populations)					
	End-of-Life Counseling HCPCS (S0257)	Advanced Care Planning CPT (99497, 99498)	Home/Community Inter-disciplinary Care Team Consult CPT (99341-99350)	Inpatient/Outpatient Inter-disciplinary Care Team Consult CPT (99366, 99368)	Individual, Family, Marriage Counseling, In-Home CPT (99510)	Respite, In-Home HCPCS (T1005)
NM		✓	✓			
NY			✓			
NC			✓			✓
ND			✓	(99366 only)		
OH		✓	✓	✓		
OK			✓	✓		✓
OR			✓			
PA			✓			
SC		✓	✓		✓	
SD			✓	(99366 only)		
TX			✓			
UT		✓	✓	✓		
VT			✓	✓	✓	✓
VA	✓	✓	✓	✓	✓	✓
WA	✓	✓	✓	✓		
WV			✓			
WY			✓	(99366 only)		
<b>Total:</b>	5 States	17 States	42 States	19 States	6 States	14 States

Note: NASHP reviewed CPT and HCPCS codes that California and other states use to pay for individual palliative care services in inpatient, outpatient, or community settings. NASHP’s findings in Table 2 highlight how state Medicaid agencies are reimbursing for these codes, but it is difficult to draw further conclusions about how or whether these state Medicaid programs specifically support palliative care.

## Appendix D: Palliative Care and the way to health equity: what the Council is reading

### Readings:

- Sederstrom, PhD, MPH, MA, FCCP. 2020, May 7. [Bioethics.net. Unblinded: Systematic Racism Institutional Oppression and Colorblindness](http://www.bioethics.net/2020/05/unblinded-systematic-racism-institutional-oppression-and-colorblindness/) (<http://www.bioethics.net/2020/05/unblinded-systematic-racism-institutional-oppression-and-colorblindness/>).
- CAPC’s blog posts on [Implicit Bias and Its Impact on Palliative Care](https://www.capc.org/blog/palliative-pulse-palliative-pulse-june-2017-implicit-bias-and-palliative-care-part-1/) (<https://www.capc.org/blog/palliative-pulse-palliative-pulse-june-2017-implicit-bias-and-palliative-care-part-1/>) and [Using Palliative Care to Support Equitable Care in the Midst of COVID-19](https://www.capc.org/blog/using-palliative-care-support-equitable-care-midst-covid-19/) (<https://www.capc.org/blog/using-palliative-care-support-equitable-care-midst-covid-19/>).
- Carson, PhD. 2020. Prisoners in 2018. *U.S. Department of Justice. Office of Justice Programs. Bureau of Justice Statistics.*
- Flaherty. 2020, July 14. Flaherty. 2020, July 14. [A Bad Fit? Study finds the concept of faculty fit in hiring is vague and potentially detrimental to diversity efforts.](https://www.insidehighered.com/news/2020/07/14/study-concept-faculty-fit-hiring-vague-and-potentially-detrimental-diversity-efforts?fbclid=IwAR3crXSG9sl6wKpMji9_OsUDQNAFHxwGkn7E4D75VsWbDY5dFAAbyk2D064) *Inside Higher Ed.* ([https://www.insidehighered.com/news/2020/07/14/study-concept-faculty-fit-hiring-vague-and-potentially-detrimental-diversity-efforts?fbclid=IwAR3crXSG9sl6wKpMji9\\_OsUDQNAFHxwGkn7E4D75VsWbDY5dFAAbyk2D064](https://www.insidehighered.com/news/2020/07/14/study-concept-faculty-fit-hiring-vague-and-potentially-detrimental-diversity-efforts?fbclid=IwAR3crXSG9sl6wKpMji9_OsUDQNAFHxwGkn7E4D75VsWbDY5dFAAbyk2D064))
- Hardeman, Ph.D., M.P.H., Medina, M.D., M.P.H. and Boyd, M.D., M.P.H. (2020). Stolen Breaths. *The New England Journal of Medicine.*
- Kendi. 2020, June 1. [The American Nightmare: To be black and conscious of anti-black racism is to stare into the mirror of your own extinction.](https://www.theatlantic.com/ideas/archive/2020/06/american-nightmare/612457/) *The Atlantic* (<https://www.theatlantic.com/ideas/archive/2020/06/american-nightmare/612457/>)
- Menakem, Resmaa. 2017. My Grandmother’s Hands: Racialized Trauma and the Pathway to Mending Our Hearts and Bodies.
- Melaku and Beeman. 2020, June 25. [Academia Isn’t a Safe Haven for Conversations About Race and Racism.](https://hbr.org/2020/06/academia-isnt-a-safe-haven-for-conversations-about-race-and-racism?fbclid=IwAR3esS7bzYI34Lw8ripuGs4Sz9byfDKfyBj0_FtpcbuciMsDEPENwx0SUnE) *Harvard Business Review* ([https://hbr.org/2020/06/academia-isnt-a-safe-haven-for-conversations-about-race-and-racism?fbclid=IwAR3esS7bzYI34Lw8ripuGs4Sz9byfDKfyBj0\\_FtpcbuciMsDEPENwx0SUnE](https://hbr.org/2020/06/academia-isnt-a-safe-haven-for-conversations-about-race-and-racism?fbclid=IwAR3esS7bzYI34Lw8ripuGs4Sz9byfDKfyBj0_FtpcbuciMsDEPENwx0SUnE))
- Obermeyer et al. 2019, October 25. [Dissecting racial bias in an algorithm used to manage the health of populations.](https://science.sciencemag.org/content/366/6464/447) *Science* 366, 447–453. (<https://science.sciencemag.org/content/366/6464/447>)
- Tweedy, MD. 2016. [Black Man in a White Coat. A Doctor’s Reflections on Race and Medicine.](https://us.macmillan.com/books/9781250105042) (<https://us.macmillan.com/books/9781250105042>)
- Washington. 2016. [Medical Apartheid.](https://bookshop.org/books/medical-apartheid-the-dark-history-of-medical-experimentation-on-black-americans-from-colonial-times-to-the-present/9780767915472?aid=8945) (<https://bookshop.org/books/medical-apartheid-the-dark-history-of-medical-experimentation-on-black-americans-from-colonial-times-to-the-present/9780767915472?aid=8945>)
- Roberts. 2012. [Fatal Invention.](https://bookshop.org/books/fatal-invention-how-science-politics-and-big-business-re-create-race-in-the-twenty-first-century/9781595588340?aid=8945) (<https://bookshop.org/books/fatal-invention-how-science-politics-and-big-business-re-create-race-in-the-twenty-first-century/9781595588340?aid=8945>)

### Videos/Media/Podcasts (Some more specifically focused on racism):

- [CAPC Information on COVID-19](https://www.capc.org/covid-19/health-equity/information-covid-19/) (<https://www.capc.org/covid-19/health-equity/information-covid-19/>)
- [David Jones Media. \(2020, June 9\). How Can We Win Kimberly Jones \[Video\]. YouTube](http://www.youtube.com/watch?v=llci8MVh8J4) ([www.youtube.com/watch?v=llci8MVh8J4](http://www.youtube.com/watch?v=llci8MVh8J4)).

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

- [Race Forward What is Systemic Racism? Video series \(https://www.raceforward.org/videos/systemic-racism\)](https://www.raceforward.org/videos/systemic-racism)
- [Magnolia Pictures. \(2017, February 22\). \*I Am Not Your Negro\*. \[Video\]. YouTube. \(www.youtube.com/watch?v=VXfzFh0eBZQ\)](https://www.youtube.com/watch?v=VXfzFh0eBZQ)
- [Seeing White Podcast \(https://www.sceneonradio.org/seeing-white/\)](https://www.sceneonradio.org/seeing-white/)
- [Dirt. \*White Fragility Mixtape\*. \(2020, June 3\). \(https://www.dirtmv.com/writing/white-fragility-mixtape\)](https://www.dirtmv.com/writing/white-fragility-mixtape)
- [Brene Brown. \*Unlocking Us\*. https://brenebrown.com/unlockingus/](https://brenebrown.com/unlockingus/)
- [Pod Save the People by Organizer and activist DeRay Mckesson, explores news, culture, social justice, and politics with fellow activists Brittany Packnett Cunningham and Sam Sinyangw and writer Dr. Clint Smith. \(https://crooked.com/podcast-series/pod-save-the-people/\)](https://crooked.com/podcast-series/pod-save-the-people/)
- [Borge. \(2019\). \*Carol Street\*. Vimeo \(https://vimeo.com/313846948\).](https://vimeo.com/313846948)

### Activities:

- [Harvard University: Implicit Association Test \(IAT\) \(https://implicit.harvard.edu/implicit/takeatest.html\)](https://implicit.harvard.edu/implicit/takeatest.html)

## Appendix E: Minnesota Rural Urban Commuting Codes (RUCA) Explained<sup>1</sup>

These county groups are derived from the rural-urban commuting area codes developed by the United State Department of Agriculture – Economic Research Service in an attempt to define geographic areas not entirely reliant on population alone. These codes incorporate population density, urbanization, and daily commuting to define a geographic area. Below is the 10 primary RUCA codes, which are also grouped into the 4 geography types.

### Urban Definition

- Census tract is situated at the metropolitan area’s core and the primary commuting flow is within an urbanized area of 50,000 residents or more.
- Census tract is within a metropolitan area and has higher primary commuting (30% or more) to an urbanized area of 50,000 residents or more.
- Census tract is within a metropolitan area and has lower primary commuting (10-30%) to an urbanized area of 50,000 residents or more.

### Large Town Definition

- Census tract is situated at a micropolitan area’s core and the primary commuting flow is within a larger urban cluster of 10,000 to 49,999 residents.
- Census tract is within a micropolitan area and has higher primary commuting (30% or more) to a larger urban cluster of 10,000 to 49,999 residents.
- Census tract is within a micropolitan area and has lower primary commuting (10-30%) to a larger urban cluster of 10,000 to 49,999 residents.

### Small Town Definition

- Census tract has a primary commuting flow within a small urban cluster of 2,500 to 9,999 residents
- Census tract has higher primary commuting (30% or more) to a small urban cluster of 2,500 to 9,999 residents.
- Census tract has lower primary commuting (10-30%) to a small urban cluster of 2,500.

### Rural Definition

- Census tract has a primary commuting flow outside of urban areas and urban clusters.

---

<sup>1</sup> [County categories for rural-urban commuting areas map \(https://www.ruralmn.org/rural-urban-commuting-areas-explanation-of-county-categories/ruca-county-map/\)](https://www.ruralmn.org/rural-urban-commuting-areas-explanation-of-county-categories/ruca-county-map/)

## Appendix F: Council Members

Name	Seat	Term End Date
VACANT	Care Coordinator	10/1/2023
Erin Balbach	Registered Nurse or Advance Practice Nurse	10/1/2022
Jody Chrastek	Registered Nurse or Advanced Practice Nurse (NBCHPN Certified)	10/1/2023
Karen Gervais	Member	10/1/2023
Audrey Hansen	Member	10/1/2022
Jessica Hausauer	Patient or Personal Caregiver, Chair	10/1/2023
Intisar Hussein	Licensed Social Worker	10/1/2022
C Scott Kammer	Health Plan Representative	10/1/2023
Deborah Laxson	Patient or Personal Caregiver, Vice-Chair	10/1/2022
Kirstin LeSage	Physician	10/1/2022
Elizabeth Mahan	Care Coordinator (Spiritual Counselor)	10/1/2022
Julie Mayers Benson	Physician (ABHPM Certified)	10/1/2023
Carol Shapiro	Patient or Personal Caregiver	10/1/2022
Dannell Shu	Patient or Personal Caregiver	10/1/2023
Adine Stokes	Licensed Health Professional	10/1/2022
Virginia Thompson	Licensed Health Professional	10/1/2023
Karen Wald	Licensed Health Professional	10/1/2022
VACANT	Physician Assistant (ABHPM Member)	10/1/2020

Membership of the Palliative Care Council must include:

- Two physicians, of which one is certified by the American Board of Hospice and Palliative Medicine;
- Two registered nurses or advanced practice registered nurses, of which one is certified by the National Board for Certification of Hospice and Palliative Nurses.
- One care coordinator experienced in working with people with serious or chronic illness and their families.
- One spiritual counselor experienced in working with people with serious or chronic illness and their families.
- Three licensed health professionals, such as complementary and alternative health care practitioners, dietitians or nutritionists, pharmacists, or physical therapists, who are neither physicians nor nurses, but who have experience as members of a palliative care interdisciplinary team working with people with serious or chronic illness and their families.
- One licensed social worker experienced in working with people with serious or chronic illness and their families.
- Four patients or personal caregivers experienced with serious or chronic illness.
- One representative of a health plan company.

## MINNESOTA PALLIATIVE CARE ADVISORY COUNCIL

- One physician assistant that is a member of the American Academy of Hospice and Palliative Medicine.
- Two members from any of the categories described in 1-9 above.

In addition:

- Council membership must include, where possible, representation that is racially, culturally, linguistically, geographically, and economically diverse.
- The council must include at least six members who reside outside Anoka, Carver, Chisago, Dakota, Hennepin, Isanti, Mille Lacs, Ramsey, Scott, Sherburne, Sibley, Stearns, Washington, or Wright Counties.
- To the extent possible, council membership must include persons who have experience in palliative care research, palliative care instruction in a medical or nursing school setting, palliative care services for veterans as a provider or recipient, or pediatric care.
- Council membership must include health professionals who have palliative care work experience or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings, including acute care, long-term care, or hospice, with a variety of populations, including pediatric, youth, and adult patients.