DEPARTMENT OF HEALTH

Palliative Care Advisory Council

LEGISLATIVE REPORT

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Palliative Care Advisory Council Legislative Report

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Executive Summary

In 2017, the Palliative Care Advisory Council was commissioned by the legislature under the leadership of the Commissioner of the Department of Health. The Legislature defined three responsibilities for the Council: to assess the availability of palliative care in MN; to analyze barriers to greater access to palliative care; and to create recommendations for legislative action.

The Council considers Palliative Care to be a fundamental component of quality medical care. It is patient-and family-centered care that ideally begins at the time of a diagnosis, and continues throughout the course of a serious illness**.** Palliative Care provides support to the patient and their family members as they address questions pertaining to care, treatment, possible side effects, and emotional well-being. The Council's collective vision for palliative care is that all Minnesotans have access to high quality Palliative Care across populations, care settings, and geography.

During 2018, the Council identified its working definition of Palliative Care, developed essential infrastructural components and preliminary collective action processes for its work, completed a pediatric palliative care assessment, determined its seven work group priority areas via a strategic planning session, and explored whether and how to be involved in the creation of a state plan for palliative care. Furthermore, an MDH intern completed a review and analysis of legislative work done by other palliative care councils across the nation. The Council chose seven core focus areas for its study, analysis, and recommendations, and established a work group structure for each. These are the Council's seven priority areas:

- Education & Training
- Research, Metrics & Data
- Delivery Models and Standards of Practice
- Policy
- Awareness
- Reimbursement & Sustainability
- Access for All

A summary of the findings of the Council's seven work groups are outlined in this report. Some of the work groups have identified potential recommendations. The larger Council has yet to prioritize and bring those recommendations forward for legislative consideration. However, due to the anticipation that legislation around pain and opioid misuse is highly likely in the 2019 legislative session, the Council directed its Policy Work Group to provide direction to lawmakers, given the need to balance the relationship between policies addressing addiction and policies supporting quality palliative care. Lawmakers' recommendations should consider addiction and pain management policies based upon the latest research, best practices and expert input. The Council's Policy Work Group provides considerations to legislators in this regard.

In 2019, the Council intends to refine its recommendations based upon stakeholder engagement in order to identify gaps and new ideas in palliative care, and develop a strategy to engage the legislature.

Background

In 2017, the legislature authorized the creation of a Palliative Care Advisory Council (the Council) under Minnesota Statutes, section 144.059 (Statutes, 2017). The Council was directed to assess the availability of palliative care in the state of Minnesota, analyze barriers to greater access to palliative care, and make recommendations for legislative action. The membership of the Council is highly specified. It includes health professionals who have palliative care work experience with patients of all age groups, or expertise in palliative care delivery models from inpatient, outpatient and community settings, including acute care, long-term care and hospice. The Council also includes patients and family caregivers with firsthand experience with palliative care. For a listing of members and their respective classification, see Appendix A.

In June 2018, a small Council Work Group, with input from the larger group, created the Council's three-part explanation of its working definition of palliative care:

WHAT is Palliative Care?

- Palliative Care is patient and family-centered care to address physical, social, emotional and spiritual needs for those living with serious or life-threatening illness.
- Palliative Care is provided by a team of medical providers, social workers, chaplains and others.
- Palliative Care can be provided along with treatments intended to cure.

WHO benefits?

- Palliative Care focuses on providing relief from the symptoms and stress of serious illness for patient and family.
- Palliative Care is appropriate at any age and any stage of serious illness.

WHY is it needed?

- Palliative Care facilitates patient autonomy by identifying patient and family goals, values, and preferences.
- Palliative Care supports informed decisions.
- Palliative Care provides "an extra layer of support" for patient and family.

The Council views Palliative Care, understood in this way, to be essential to high quality medical care. It is ***patient and family-centered care*** that ***can begin at the time of a diagnosis*** and ***continue throughout the course of a serious illness***. Palliative Care provides ***support*** to the patient and their family members as they ***address questions*** pertaining to care, treatment, possible side effects, and emotional well-being.

Summary of Progress Made on the Council's 2018 Impact Agenda

Over the course of 2018, the Council focused on the four main priorities it identified in its 2017 report to the Legislature for the future of palliative care in Minnesota:

1. *Define the long-term 2025 vision, or the "to be" state;*

   Update: The council members each were individually asked to identify their long-term goals for 2025 prior to their strategic planning retreat. Those individual goals were shared with the entire Council. At their last meeting in December 2018, the Chair brought forth a vision statement for the group to consider. After some discussion, the Council created the following vision statement: *"All Minnesotans have access to high quality Palliative Care across populations, care settings, and geography".*

2. *Document the gaps between the "as is" (2018) and "to be" state (2025);*

   Update: The Council took a more in-depth look at gaps in pediatric palliative care in 2018. Through funding from the Minnesota Department of Health (MDH) Comprehensive Cancer Control Program and in partnership with the Minnesota Network of Hospice & Palliative Care, the Pediatric Palliative Care Coalition of MN and the University of Minnesota's Community Health Initiative, an assessment of palliative care professionals and availability of pediatric palliative care was conducted. The assessment identified a gap in pediatric hospice services in some northern and southern counties. A much larger gap was identified for pediatric palliative care services that encompass northern and southern MN, with the exception of Kittson, Wabasha, Dodge, Olmsted and Fillmore counties. The assessment found that there is a gap in formal training for the pediatric population, even in organizations providing pediatric care. In an effort to improve access to pediatric palliative care, more education, incentives, and resources for health professionals were identified as a need to ensure professionals have the tools and support they need to fill this gap.

3. *Create a strategic plan to reduce the identified gaps between "as is "and "to be" states of palliative care.* The strategic plan will include the goals, objectives and strategies required to successfully implement the long-term vision and fulfill the Council's legislative mandate. The plan will include monthly deliverables through June 2019; quarterly deliverables for July 2019 through December 2020; and annual deliverables for 2021 through 2025; and will be reviewed no less than annually.

   Update: Early in 2018, the Council completed a daylong strategic planning session and identified seven priority areas. Work groups around six of the seven areas were formed, each now at different stages of development. The processes for working together are in creation, as well as the process for determining legislative priorities. Various work groups have identified many priorities, but the larger Council has agreed upon no legislative priorities at this time. A report on the strategic planning work and reports from the work groups is in the Strategic Priorities and Work Group Summaries sections of this report.

4. *Determine the working infrastructure (e.g. by-laws) required for the Council*. This work is to assist the Council in successfully achieving its three legislative directives, as well as effectively pursuing its long-term vision for palliative care in Minnesota in 2025.
   Update: A small work group drafted by-laws after reviewing by-laws from various organizations. On March 13, 2018, the Council approved its by-laws. (See attached Appendix B). Additionally, the Policy work group determined a protocol for signing letters of support on legislative actions deemed worthy by the Council. During this past year, the Council worked out methods to sign onto letters of support such as the Federal Palliative Care and Hospice Education and Training Act (PCHETA).

Strategic Priorities

In April 2018, the entire Council, with financial support from a small annual plan with the MDH Comprehensive Cancer Control Program, met for a daylong strategic planning retreat. The group learned a bit about each of its members, heard the goals members had for palliative care in 2025 and then spent the majority of their time brainstorming ideas on what MN would have in the future if palliative care were available to all. From this brainstorming session, the Council identified the following seven core focus areas:

Figure 1: Council Core Focus Areas

Members then self-selected into one of six groups to determine what the areas of work would be; what the desired outcomes would look like; and identify what organizations and people would be engaged in the focus area. The whole group rather than a sub group addressed the priority area "Access for All".

Table 1: Council Priority Areas Outcomes and Engagement Identified in April 2018

Focus Area	*Areas of Work*	*Desired Outcomes*	*Orgs/People Engaged in Focus Area*
Awareness	• Leverage various mediums to create awareness including: videos, PSAs, social media, pamphlets, short "take-aways", CCTV in medical settings, PBS/MPR interviews, city/county/state fairs, awareness walks • Increase marketing of the PC need/cause through: bumper stickers, billboards, pharmacy PSAs, publicity events at sporting venues, public speakers, digital banners • Note: awareness efforts need to be segmented by "audience" and there's generally a need to clarify between palliative care and hospice	Patients/families have understanding of available services via: medical providers, insurance case managers, community resources, faith/interfaith communities, cultural communities, outreach PSAs, legislators, NPOs, HR departments	Insurance companies, health systems (Allina, HP, HCMC, etc), Associations (Alz, Cancer, MNHPC, AHA/MN, ARC, Open Arms, etc), Wilder, home care agencies, large employer foundations, community health clinics, cultural communities, national and local foundations (including Mpls and St. Paul), Governor's office
Research, Data & Metrics	• Identify and analyze available data • Identify data gaps (topic and type of data) • Consider different methods/purposes • Identify mandatory metrics	An initial assessment is created followed by a comprehensive assessment, which would be leveraged on an ongoing basis into the future.	MHA, AHPM What Matters, MNHPC (peds palliative care, evaluation data, Live Well at Home), ICSI, CAPC, CMS guidelines, Health insurers, MMA ASIC Hub, MDH, Stratis, MHCA, MBA, Alzheimer's survey, Ed Rattner, DHS, Board of medical practice, graduate students (St. Mary's, U of MN, etc)

Focus Area	*Areas of Work*	*Desired Outcomes*	*Orgs/People Engaged in Focus Area*
Reimbursement, Sustainability & Delivery Models	• Explore value beyond hospital context • MHRA • EHR interoperability • Demo projects – extensive care model (CAPC) • Measurement: total cost of care, quality (clinical and experience), number of providers • Engage community-based resources (e.g. CHWs, block nurses) *Delivery Models* • *ACP → integration into the point of care* • *Avoid ED/crisis/hospital admissions* • *First step: palliative care, last step: ED/hospital settings*	• Universal coverage of palliative care and hospice • Extended coverage of palliative care and hospice • Work groups exist on: 1) policy/advocacy and 2) reimbursement/sustainability • New innovative funding mechanism exist especially for proof of concept/novel approaches	Partners and Collaborators DHS, MDH, CMS/CMMI, county agencies, other states and councils Advocacy Groups & Collaborations ACS, NORD, NKF, Act on Alzheimer's, AARP Organizations Stratis, CAPC, MMA/Olivia Mastry, MCHP, MNHPC/NHPCO, ICSI, NCP4ACP, AAAPM, other specialty societies
Standards of Practice	Create an ethical obligation for practitioners to foster palliative care competence and capacity • Quality standards • Integration between primary care and hospice • Accreditation/regulation (regulation must be necessary for all who practice palliative care without accreditation) • Explore what accreditation looks like for differing needs (e.g. a big system vs. an individual provider; an urban provider vs. a rural provider)	TBD	TBD

Focus Area	*Areas of Work*	*Desired Outcomes*	*Orgs/People Engaged in Focus Area*
Education & Training	• Learners (didactic and clinical):Students: medical, PA, RN, NP, Pharmacy, PT/OT/SLP, CPE et al, SW interns, Residents, high schools • Workforce – specialty and primary PC: interpreters, generalists, home health, specialty providers, SW, RN, CAN, chaplains, PT/OT/SLP/RT HCBS, PharmD, administration, public health • Public/community – Awareness and skills for: family, caregivers, churches, general public	• Competency of a minimal palliative care skill set is clear and being pursued This would include ACP and GOC, symptom management, communication, when to refer to specialty palliative care, identifying non-physical stressors, bereavement (surrogates), documentation • Advanced skill training is accessible to all	Undergraduate and graduate programs, Honoring Choices, MNHPC, CPE Leaders, CAPC, MMA (and Respecting Choices and Ariadne Labs), Vocational colleges, PCNow, VitalTalk, Stanford, CSU, POLST committee, advocacy groups, Stratis, Board of Medical Practice
Policy (formerly Advocacy and Policy)	• Asset mapping – personal and organizational connections • Actions around legislation – deliver annual report in October/November and meet with legislators on the report • Connect with other states' palliative care advisory councils • Identify resources that could support council work • Identify who might be resistant to the council's work • Track/monitor relevant policy debates • Map council members' legislative districts • Create a story bank by leveraging research, data, and stories; consider "the face" of PC	1. Identify/determine policy levers (big 'p') at state and federal levels 2. Identify/determine policy levers (small 'p') or system change levers to go beyond #1 3. Identify clear, informed "asks" 4. Clarify what the council can and can't do, should and shouldn't do	ACS, ACS-CAN, AHA (big voluntary orgs) Orgs that signed to support this legislation MDH, DHS liaison (legislative) Master's and PhD students, AARP, MN Aging (policy council) Medical orgs (pediatrics, nurses, MMA) Payers and institutions

Focus Area	*Areas of Work*	*Desired Outcomes*	*Orgs/People Engaged in Focus Area*
Access for All	• Research what palliative delivery means and looks like across various contexts (culture, geography, etc.) • Engage people and families from communities to understand what palliative care means across cultural communities and use learnings to define PC in a way that holds all cultural practices • Create a statewide approach to palliative care accessibility within the context of various factors: care settings, populations (including cultural and ethnic, underinsured and uninsured, LGBT, age-specific groups), and geography • Identify county-level differences in funding and reimbursement • Foster an ethical obligation to serve palliative care needs (akin to "do no harm")	• Same level of care no matter who or where you are – "boundless reach" • Comprehensive disease/symptom management is achieved • Increased quality • Disparities are addressed and improved upon • There are fewer end of life standoffs • Increased number of dignified deaths • Reduced health care costs and increased patient and provider satisfaction • There are fewer crises and more support through transitions • Increased medical decisions that are rooted in patient values • Improved health care metrics (e.g. LOS in hospice before death, ICU days in last 6 months, reduce EOL costs, ACPs are honored)	MNHPC (especially re: racial/ethnic communities and stories project), Stratis, Pediatric Palliative Care Council, AAAs (inc. Land of the Dancing Sky), Wilder, disease-specific organizations, small/private hospitals and clinics, community PC provided by small hospices, Training to Serve, LSS parish nursing care, ARC and other disability orgs, Pacer, Tribal nations and IHS, Crescent Care, VA, Bureau of Indian Affairs, MN and US association of PAs

Work Group Summaries and Recommendations

The following is a report of the work group's findings and recommendations since their strategic planning retreat in April determined the scope of work of each work group through December 2018. There currently is no work group on Access for All. The larger Council has not voted on recommendations by work groups at this time. As a result, no legislative recommendations beyond maintaining the Council and its funding have moved forward from the Council.

Awareness Work Group

As referenced in the 2018 Legislative report, the Minnesota Network of Hospice & Palliative Care conducted the first comprehensive statewide survey of end-of-life needs of older Minnesotans in 2011. The survey found that 68% of 400 Minnesotans ages 50-80 had no knowledge of, or had never heard of, palliative care. Of the 32%

who had heard of palliative care, most were unsure of what the term means (Cotroneo, 2011). The awareness work group reports there are a limited number of current surveys completed and summarized in the last 12 months. Anecdotally, members of this group report there is a continued lack of awareness of palliative care.

One recent study reported that in a national survey, 46% of respondents had at least heard of palliative care, but that basic knowledge was lacking on the subject (Koslov, 2018). Currently, an MPH student at the University of Minnesota School of Public Health is analyzing data from the Health Information National Trends Survey (HINTS) to describe patterns of palliative care knowledge and identify trusted sources of information about palliative care. This may provide further data and direction concerning the awareness challenges regarding palliative care.

Education and Training Work Group

The Education and Training Work Group did an extensive analysis of both primary and specialty palliative care education in Minnesota. Below is their summary of findings and recommendations.

What do we know about Primary Palliative Care?

There is general agreement that primary palliative care skills are needed for anyone who works with people who have serious or potentially life-threatening illness. Those skills include basic pain and symptom management; initial goals of care discussions; shared decision making and avoiding one's own agenda in goal setting; understanding the ethical principles of care for the seriously ill; how to screen and attend to whole person needs; and basic understanding of end of life needs for patients, families and caregivers. There is a lot less known about how primary palliative care is taught in the State of Minnesota. There are no formal requirements for primary palliative care education and there are no standard competencies for professionals in training. For physicians, there are electives available in some settings for medical students and residents, however, they are not required and often not encouraged unless a student/resident expresses their own interest to a mentor first. Some medical schools, such as the University of Minnesota-Duluth campus, have instituted their own curricula for end of life care. However, education specifically about palliative care and primary palliative care skills tends to be minimal and there is no agreed upon standard in our state. Nursing schools, social work schools, physician assistant and chaplain training programs (such as CPE) also have no minimum standard for primary palliative care skills or education in their training programs.

Many resources are now available to those that have available funds, but the group could only find a few well-organized sources out there with free educational materials (Stanford Health Palliative Care Training Portal and portions of Vital Talk). Most primary palliative care education comes with a fee such as California State University (CSU) courses, Center to Advance Palliative Care (CAPC) courses and Harvard courses. Smaller healthcare systems, rural areas and institutions that offer services to the underserved often do not have the funds needed to access training for their entire healthcare staff, community and administration. Larger institutions can also have issues even utilizing their own specialists due to the overwhelming need for their skills in clinical work. There is also no coordinated effort or agreed upon standard to help guide those institutions that may have the money, but do not understand the need, the value or where to start. Competing priorities in healthcare and our predominantly fee-for-service healthcare models, have caused a climate where palliative care education tends to be under prioritized and therefore, not funded.

What do we need to know?

We need to better understand the educational system's barriers to improved primary palliative care education and training. Whether it be understanding of the goals of palliative care, competing interests, funding, access to specialty educators, perceived value or other, we will need to understand why it has not become a priority in the educational institutions and healthcare systems of our state. We also need to better understand what *is* currently being offered under the definition of "primary palliative care" to help institutions create more robust training in these areas. It will be difficult to learn what all universities and health systems offer, so sampling a variety of institutions will likely help us understand. Although primary palliative care education is needed in all areas of healthcare, we believe that focus needs to start with provider training, both in primary care and certain specialties with high levels of patients with serious or life-threatening illnesses (internal medicine, family practice, pediatrics, general surgery, internal medicine specialties, cancer care, geriatrics). There are communication and whole person assessment skills intrinsically built into the training of chaplains, social workers and nurses. This training is much less common in physician training. Physicians are often leaders of the healthcare team, thus it is imperative that education is mandated to this population.

What do we know about specialty palliative care?

Upon review of the known formal palliative care specialty education options, we found that most of the specialty level training for the core Interdisciplinary Team (IDT) is well defined. There are fellowships for physicians, nurse practitioners and social workers. There are certification programs for nurse practitioners, registered nurses, chaplains and social workers. Certificate programs (contrasted to certification programs) are increasingly available; however, they require much less training, education, clinical hours and time and are not usually considered specialty training by themselves. There are also newer, more generalized programs available to any team member including a palliative immersion program and several formal Master of Science in palliative care programs. Depending on the team member role, minimum standards in certification programs are not always consistent between programs, but they tend to focus on the standard realms of palliative care education such as communication, ethics, shared decision making, eliciting goals of care, symptom management, and whole person care. The 4th edition of the Clinical Practice Guidelines for Quality Palliative Care were released earlier this year (Care N. C., 2018). They are the gold standard for specialty palliative essentials and should guide educational focus for specialists and specialist teams.

For physicians, there are fellowships throughout the country; our state having two fellowship programs with 8 filled positions in 2018. We have both adult and pediatric tracks available in Minnesota. Standards for fellowship are well defined and monitored by large governing bodies such as the American Board of Medical Specialties and the American Osteopathic Association. More recently, there has been development and promotion of a formal certification for hospice medical directors, acknowledging that this is a unique non-clinical skill set due to the need for detailed knowledge of Medicare regulations. It is becoming more recognized that the role of Hospice Medical Director requires specific training separate from the clinical training the fellowship provides.

For nurse practitioners, formalized specialty training is available through a few different paths. The Advanced Certified Hospice and Palliative Nurse (ACHPN) certification is probably the longest standing and well-known track. It is earned through formalized knowledge testing and ongoing practice requirements for continued certification. The requirements for initial certification often take 1-2 years to complete. Another specialty training option is a formalized, accredited APRN (Advanced Practice Registered Nurse) fellowship. These are still rare but gaining momentum and available in six states (none in the Midwest, most are on the East coast). They focus on clinical skills, role development and quality improvement. Schools of Nursing have MSN (Master of

Science in Nursing) subspecialty courses available intended for nurse practitioners who have completed their primary training and would like further specialty training in palliative care. Registered nurses can also do formalized training to obtain certification called CHPN (certified hospice and palliative care nurse), which also takes 1-2 years to obtain depending on hours spent doing direct palliative care nursing.

Chaplains have formalized specialty training in the form of the BCC-PCHAC (Board Certified Chaplain-Palliative Care and Hospice Advanced Certification) through the APC (Association of Professional Chaplains). The certification has significant requirements, taking a minimum of 3 years to obtain after one is board certified through the APC or NACC (National Association of Catholic Chaplains). Certification is somewhat controversial because one must be a BCC through the APC or NACC to apply for the specialty board certification. Other chaplain board certifications available do not align with completion of the BCC-PCHAC certification. The College of Pastoral Supervision and Psychotherapy (CPSP) also has specialty hospice and palliative care certification available. Other palliative certificates are available, but the requirements vary, and certificates are not the standard for specialty palliative care. Many CPE (clinical pastoral education) programs have electives in hospice, hospital palliative units or similar, which in combination with certification is likely the best path to training for specialty palliative care chaplaincy.

Master's level and bachelor's level social workers can do specialty certification programs. The master's program takes a minimum of 2 years to achieve. There are both clinical hour requirements and specialty CEU requirements. The resulting certification is the Advance Certified Hospice and Palliative Social Worker (ACHP-SW). Bachelor's level program takes a minimum of 3 years to achieve with similar CEU requirements. The resulting certification is the Certified Hospice and Palliative Social Worker (CHP-SW). Social workers also have fellowship programs available; one is available at the University of Minnesota. It is a 12-month program offered to Masters level social workers with either LGSW, LICW or LICSW licenses. The goal is to train leaders in clinical palliative care social work with a focus on collaboration and advocacy.

Physician Assistants are the only core team member that currently have no formal specialty training available in palliative care. There are Certifications and Added Qualification (CAQ's) in other subspecialties such as cardiovascular/thoracic surgery, emergency medicine and hospital medicine. CAQ's are not available in palliative care. There is ongoing discussion at the national level about the benefits and potential pitfalls of creating specialty requirements for physician assistants in palliative care. At this time, there is no minimum agreed upon standard to be considered a specialty palliative care physician assistant.

For any team member, specialty education can be obtained through either a graduate certificate in Palliative Care or a Master's in Science in Palliative Care. There are two programs available in the United States for a Master of Science in Palliative Care, neither in the Midwest. They are intended for mid-career professionals in any profession including MD (medical doctor), DO (doctor of osteopathy), PA (physicians assistant), SW (social worker), chaplaincy and nursing. The last formalized specialty training is the Palliative Care Immersion Program offered through Four Seasons in North Carolina. This program focuses training on clinical skills, financial sustainability, billing/coding and program development.

A Caveat: The Education and Training work group acknowledges the many important interdisciplinary team roles that we have not yet addressed including pharmacists, music therapists, volunteers, CNA's, parish nurses, care coordinators, and family members/caregivers/general public just to name a few. They will need to develop a way to address the likely 100's of potential parties that have a stake in the education recommendations.

Policy Recommendations from the Education Work Group:

The Education Work Group believes that the only way the workforce shortage in specialty palliative care is going to improve is through mandatory education early in the training of healthcare professionals. There should be mandatory education regarding the definition, goals and value of palliative care in professional programs such as medical schools, certain residency programs (FP, IM, general surgery, pediatrics, certain medical specialties), and master's level chaplain, nursing, physician assistant and social work programs. Education in bachelor's level programs should be focused to those roles that have the potential for specialty level positions such as RN and SW. By making this education mandatory, it will help spark the interest of pursuing careers in specialty practice.

Education of primary palliative care knowledge and skills needs to be available and mandated for all healthcare workers, healthcare administrators and learners going into healthcare careers. We recommend the focus be two-fold – the current workforce and the learners. These two groups of people will need different plans moving forward. We recommend that the current workforce be mandated through the state licensing bodies for specific CME/CEU's each year dedicated to primary palliative care skills. General information about palliative care, whole person pain management and communication skills could be good places to start for physicians, nurse practitioners and physician assistants. Consideration could be given for mandated education about palliative care skills that would be added to board and licensing tests for social workers, nurses and chaplains also. As for the "learners", there should be mandated curricula in medical schools across the state. All three medical schools in Minnesota should have minimum standards for palliative care education, no matter what specialty a physician is going into. This training needs to include basic information about what palliative care is, general overview of whole person care and disease trajectory, and the importance of family and caregivers in a person's wellness. In selected residencies, the mandatory education should become more clinically relevant and specific. This should include basic symptom management, goals of care discussions, prognosis, assessments of whole person and caregiver needs, and evaluation of capacity with designation of surrogate decision makers. Key fellowships should also have palliative care education and skills added to their Milestone programs, especially for oncology, radiation oncology, cardiology, geriatrics, critical care, pulmonology, nephrology, and surgical specialties such as neurosurgery and cardiothoracic surgery. We recommend that there be ongoing discussion about educational standards for physician assistants at the national and state level. The Standards work group likely will have more information about what standards we should recommend. We are still developing our longer-term recommendations as a work group and will likely evolve and refine as we discuss with ad-hoc members over time.

Policy Work Group

Over the course of the year, the Policy & Advocacy Work Group has determined that its efforts should be in Policy, not Advocacy. As a result, they changed their name to the Policy Work Group. This was agreed upon for two reasons. One to ensure that the Council focused on advisory work rather than implementation work, and because many council members cannot participate in advocacy because of their organizations' limitations on advocacy activities.

Since the April 2018 strategic planning meeting, the Policy work group has done several things. The group has identified a summary of state policy levers for consideration; identified a summary of current federal policy levers, especially PCHETA (Care C. t., 2017); clarified the Work Group's role in legislative recommendations as it relates to the Commissioner of Health; drafted a report summarizing the legislative work of other councils across

the United States; drafted considerations for opioid legislation; and determined a process for signing letters of support for various legislative initiatives with its inaugural sign on for PCHETA legislation support.

The state policy levers that were identified and considered by the Policy Work Group are outlined below (Sinclair, 2017)**.**

- **Regulation over Facilities-** requiring palliative care info be readily available; requiring development of standards for palliative care
- **Regulation over Clinicians-** mandating or encouraging continuing education for providers related to palliative care
- **Surveillance on Access to Care-** developing a Palliative Care Advisory Council, task force, or similar organization to assess state capacity, identify resources, and gaps, and make recommendations
- **Payment Policy-** improving access to palliative care by expanding Medicare/Medicaid coverage for these services

For further analysis of legislative possibilities within the four policy lever areas outlined above, see the Analysis of Other State Palliative Care Councils section of the report. The Policy Work Group participated in a presentation of this national analysis report from an MDH intern and as a follow up presented the findings to the larger Council. They are currently synthesizing those findings.

The Palliative Care Advisory Council is responsible in making policy recommendations about and for current and future legislation on topics related to palliative care. Topics that have received a lot of attention in the policy arena recently, are pain management and the opioid crisis. In anticipation of upcoming legislation to address the "epidemic" opioid abuse in this next legislative session, the Policy Work Group agreed at the July Council meeting to draft guidance language for legislators to ensure that palliative care needs would not be overlooked in opioid abuse legislation. These recommendations for pain management considerations are included in the Legislative Considerations section.

Reimbursement, Sustainability and Delivery Models Work Group

This work group has done a scan of different health plans and levers in the reimbursement arena to advance palliative care and/or decrease barriers to it. Promising models this work group identified include California and the Coalition to Transform Advanced Care (C-TAC). (Care C. t., 2016) The work group is considering proposing to pilot a model for palliative care across the life span for MN by utilizing a model proposed already in another state or one by C-TAC.

Research, Data & Metrics Work Group

Six assessments were reviewed by the Research, Data and Metrics Work Group. They include the:

- MNHPC Pediatric Palliative Assessment (MN Department of Health, 2018)
- CAPC Compiled Research Literature Review
- Stratus Health Rural Palliative Care Impact Report (Health S. , 2016)
- Fond du Lac Band of Lake Superior Chippewa Wiidookaage Cancer Plan 2025 (Division, 2016)
- MDH intern compiled list of Palliative Care Programs in Minnesota (by county), July 2018
- Hospice and Palliative Nurses Association Research Agenda 2015-2018 (Association, 2015)

From this review, the work group compiled a list of recommendations for policy consideration and/or action. The Council has not yet prioritized this work group's extensive list of recommendations, which include:

- Support a general increase in funding for palliative care research and clinical trials
- Develop a Palliative Care Leadership Center for the State of MN
- Minnesota Hospitals should use the CAPC self-reporting model to improve our understanding and metrics, state-wide
- Identify and Support psychosocial needs for Pediatric Palliative Care
- Encourage Pediatric Palliative Care as a focus of research
- *Promote PCAC Policy and Advocacy Work Group's initial recommendations:*
  - Connect with other states' palliative care advisory councils
  - Track/monitor relevant policy debates in Minnesota
  - Map council members' legislative districts
  - Create a story bank by leveraging research, data, and personal stories of serious illness
- HPNA Research Recommendations (2015-2018) Report:
  - Research is needed to understand effective data systems and technology infrastructure in palliative care organizations
  - Research is needed on the types of new and innovative delivery systems in palliative care
  - Research is needed to explore the effects of the hospice and palliative structural environment on patient, family and organizational outcomes
  - As it pertains to the physical aspects of care:
    - Research is needed on family management of dyspnea
    - Research is needed on dyspnea in patients unable to self-report
    - Research is needed on interventions in dyspnea
    - Research is needed to determine the role of informal caregivers in managing fatigue
    - Research is needed in the role and mechanisms of fatigue in aging populations.
    - Research is needed into cancer related fatigue
    - Research is needed to determine the role of informal caregivers in managing constipation.
  - Research is needed to standardize the definition, measurement and management of constipation in palliative care
  - And as it pertains to the translation of this research:
    - Research is needed to better understand the structural, environmental, and workforce factors that influence the implementation of evidence-based practice
    - Research is needed regarding costs and organizational needs for creating and maintaining a strong culture of evidence-based practice

Standards of Practice Work Group

The Standards of Practice Work Group created a summary of the collective understanding and defining of standards of practice. Standards of practice have been developed to provide a framework for providing quality palliative care to patients with life-limiting illnesses and their families. For the past two decades, several groups of palliative care experts have worked to define these standards. The standards can be divided into two areas – standards of *care* for delivery of care to the patient, and standards of *practice* to establish programmatic delivery of such care. Both are outlined below.

Standards of Practice for Palliative Care Programs

A Palliative Care program must include the following elements to be recognized as offering palliative care services:

1. Interdisciplinary Team (IDT): This team of individuals will work collectively to meet the physical, psychosocial, and spiritual needs of the patient and family. The team must include at least two disciplines and should include a medical provider (MD/NP/PA), RN, social worker and chaplain. Other team members could include but are not limited to a pharmacist, mental health provider, physical therapist, occupational therapist, massage therapist and volunteers. The IDT should be trained in palliative care and hold certifications if possible. At least one member should be certified in palliative care. The IDT should meet regularly to review patients and care plans. The IDT should be able to confer spontaneously if the needs of the patient require team action.
2. Assessment and management of symptoms: Upon admission to palliative care services the patient should have a comprehensive assessment of symptoms. This assessment would include pain, dyspnea, nausea/vomiting, constipation, depression, anxiety, fatigue, insomnia and spiritual distress. Upon identification of symptoms a management plan would be developed and care plan implemented. This comprehensive care plan would be documented for all IDT members to access and evolve as the patient's status changes.
3. Advance Care Planning and Goals of Care discussion and documentation: Upon admission to palliative care services the patient should have the opportunity to develop an advance care plan including consultation with family, provider or other qualified team member. The Advance Care Plan (ACP) should document a surrogate decision-maker. It should also include specific goals of care were indicated. If appropriate, these goals should be translated into Provider Orders for Life-Sustaining Treatment (POLST). Appropriate education and information about hospice services should offered and readdressed as indicated.
4. Care plan is accessible by team and other treating entities: The care plan should be customized for every patient admitted to palliative care services. This care plan should be documented in an accessible manner such as an electronic medical record. This record should be available to all IDT members and other treating entities such as hospitals, EDs or long-term care centers. Care is coordinated by the IDT and directed by the care plan. It is updated as changes occur. Furthermore, access to a member of the IDT in a meaningful manner should be provided 24/7 to provide care for patients and families in crisis.
5. Provision of care and support to family during illness and bereavement after death: The patient will define "family" and this family will be offered psychosocial and spiritual support during the illness. Assessment for caregiver burnout should be done routinely. Referrals to community resources should be provided as needed. Respite services should be offered if available to prevent caregiver burnout when identified. After the death of a patient the family should be offered bereavement services for a defined period of time. If necessary, complicated grief should be referred for ongoing care.

Standards of Care for the Patient

In November 2018, the *Clinical Practice Guidelines for Quality Palliative Care, 4th edition* were released (Care N. C., 2018). This compendium was developed by the National Consensus Project, which is made up of over 16 organizational stakeholders and individual experts in the field. Though the "guidelines should not be interpreted

as setting a standard of care" they have long been regarded as the most important and comprehensive framework defining quality palliative care.

The guidelines are divided into eight domains of care:

1. Structure and Processes of Care
2. Physical Aspects of Care
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care
5. Spiritual, Religious, and Existential Aspects of Care
6. Cultural Aspects of Care
7. Care of the Patient Nearing the End of Life
8. Ethical and Legal Aspects of Care

Each domain is subdivided into preferred practices, which can and should be integrated into the care of the patient as appropriate and indicated. Each domain also offers Essential Palliative Care Skills needed by all clinicians in addition to research evidence and even practice examples so all Palliative care programs, both mature and developing, can increase the quality of care provided to patients and families. To that end, the *Clinical Practice Guidelines for Quality Palliative Care* have been adopted as the basic standards of care for palliative care in Minnesota.

Analysis of Other State Palliative Care Advisory Councils

In July 2018, a University of Minnesota Masters in Public Health intern at the Minnesota Department of Health did an analysis for the Palliative Care Advisory Council's Legislative Work Group on the work done by other palliative care councils across the nation. According to ACS CAN, twenty-three US states have passed ACS CAN model legislation for a Palliative Care Advisory Council, including Minnesota. Thirteen others have introduced legislation (Network, 2018). The objective of this project was to explore the activities and policy recommendations made by other states' Palliative Care Advisory Councils (or non-legislative equivalents). These findings are now available to be used to inform Minnesota's Palliative Care Advisory Council in future activities and plans. The findings, outlined below, were provided to the Policy Work Group and Council at large.

Focus Area: Palliative Care Capacity, Reach and Sufficiency

California, Connecticut, Florida, Maine

Each state found areas of success and challenges. Most commonly, there was access to palliative care in urban areas but limitations in rural areas. Florida, California and Colorado have completed capacity assessments and have made their methodologies available to others. Based on the results of their assessments, their recommendations included:

- Enhance public palliative care education for both providers and patients
- Increase training/continuing education programs with advanced certification
- Standardize palliative care definition, minimum standards for programs

(Kerr, 2018) (California C. f., 2018) (Services C. D., Pending Policy & Legislation, 2018) (Committee, 2016) (Sunshine, 2018) (Council C. S., 2018) (Health C. D., 2017) (Care M. H.-o.-L., 2018) (Information, 2018)

Focus Area: Barriers to Palliative Care

Massachusetts, Oregon

These states chose to use surveys from health care providers, patients, families and facilities to better understand the barriers to understanding and effective utilization of palliative care. Based on their results, they recommended that:

- Patients, the general public and health care providers need to be made more aware of palliative care's role in chronic disease management and understand the difference between hospice and palliative care

(Health S. o., 2018) (Dahlin, 2016) (Improvement, 2018) (Council O. P., 2017)

Focus Area: Availability, Utilization and Barriers

Maryland, Texas

The Texas Palliative Care Advisory Council has been especially active in identifying barriers posed by misunderstanding and confusion of palliative care itself. These states also identified shortages of specialized resources, a lack of training in palliative care, and financial barriers to accessing palliative care services. As a result, actions and recommendations made by these councils include:

- Recognize palliative care in two branches (Supportive and Hospice)
- Improve education to clarify these two branches in clinical setting
- Support professional efforts to earn and maintain specialized credentials
- Through a Consortium of State agencies, create an educational campaign for practitioners, patients, families, and the general public to increase public awareness and improve quality of palliative care

(General, 2018) (Victoria K, 2016) (Services T. H., 2018) (Services T. H., 2016)

Analysis of State Levers

The Policy Work Group identified state levers summarized in a Health Affairs blog (Sinclair, 2017). The student intern completed additional analysis of these state levers and noted the following areas of states' legislative activity and change as of July 2017 to be:

Regulations over Facilities

New York (2010 and 2011): Public Health Law sections 2997-c and 2997-

- Requires physicians to offer information about palliative care to patients with a new diagnosis of a terminal illness, and to adopt policies and procedures to facilitate access

  (Legislature N. Y., Palliative Care Information Act, 2010) (Legislature N. Y., Public Health Law, 2011)

Massachusetts & Oregon: S 2400 & SB 608

- S 2400 (Mass.): Bill requiring licensed hospitals, skilled nursing facilities, health centers, and assisted living facilities to identify potential palliative care patients and provide them with information; developed a pamphlet available in nine languages
- SB 608 (Oregon): Similar requirement for hospitals, LTC, and residential facilities to inform patients about palliative care

(Massachusetts, 2012) (Assembly O. L., 2015)

Colorado:

- 2014 regulation that specifies standards for PC facilities (policies and procedures, goals of care, support)

(Regulations, 2014)

Regulation over Clinicians

California, Michigan, Oregon, Rhode Island, West Virginia:
- REQUIRE pain management continuing education for practitioners
- In other states, this is encouraged but not mandated

California: AB 487
- Mandates that all physicians and surgeons, except those practicing in pathology or radiology specialties, complete 12 hours of continuing education courses in pain management
- Study: Many physicians reported changing their practice as a result of these courses

New York: A 355
- Requires health care professionals who prescribed controlled substances to complete three hours of course work or training in pain management, palliative care, and addiction

(Wisconsin) (California L. o., 2001) (Leong, 2010) (Assembly N. Y., 2015)

Surveillance on Access to Care

Maryland HB 581:

- Maryland Health Care Commission conducting a pilot study of geographically diverse hospitals, developed a final report for best practices for palliative care

California: “Let’s Get Healthy California” initiative:

- Includes palliative care as a key component of strategic priority “Health Across the Lifespan” and tracks the percentage of hospitals offering inpatient palliative care

(Sinclair, 2017) (California L. G.) (Commission, 2015) (Legislature M. , 2013)

Payment Policy

The state’s role as a purchaser of health care through the Medicaid program can be a driving force for palliative care policy change. It is more common to implement a pediatric palliative care program or policy within Medicaid, although Massachusetts did implement a novel pediatric palliative care program with state funding.

California: 1915(c) waiver as part of AB 1745:

- Palliative care for children with life-limiting or life-threatening conditions resulted in an average reduction of $2,154 in Medicaid spending per enrollee per month, decrease in length-of-stay, and increase in caregiver satisfaction

Vermont: 1115(a) waiver expansion

- Offers care coordination, family/caregiver training, and therapies to eligible children and adolescents up to age 21

California: SB 1004, Palliative Care for Adults

- "Requires the Department of Health Care Services to establish standards and provide technical assistance for Medi-Cal managed care plans to ensure delivery of palliative care services"
- Early PC may accompany curative care at initial diagnosis. As condition progresses, those with serious illness who meet criteria can be enrolled in SB 1004 palliative care programs and continue to access disease modifying care.

(California A. o., 2006) (Research, 2014) (Services C. f., 2018) (Health V. D., 2018) (Services C. D., A Pediatric Palliative Care (PPC) Waiver Program, 2018) (Senate, 2014) (Keim-Malpass J, 2013) (Bona K, 2011)

Legislative Considerations

Opioid Legislative Considerations

The Palliative Care Advisory Council tasked the Policy Work Group with drafting considerations for legislators around opioid use and pain management. This group determined that recognition of the difference between chronic and acute pain must be considered as well as many other factors. The following are the recommendations they suggest lawmakers consider in pain management legislation based upon the latest research, best practices and expert input. The considerations are categorized topically for ease of reference.

Education and Engagement

- Increase provider education on pain management
- Educate providers on evidence-based non-opioid pain management options
- Require continuing education for providers in palliative care and pain management
- Promote education in communities surrounding pain management options
- Engage patients in treatment decisions about their pain management
- Address patient education and engagement, including storage and disposal of opioids to prevent these medications from being stolen or misused by others

Affordability / Accessibility

- Facilitate access to prescription drug monitoring programs
- Develop payment options for chronic pain rehabilitation
- Expand financing to provide coverage for non-opioid pain management solutions
- Develop reimbursement rates for providers surrounding pain management
  If manufacturers/pharmaceutical companies pay a stewardship fee or registration fee, we recommend that safe guards should be included in the bill that prevent manufacturers from passing on those fees to purchasers and consumers through increases of prescription opioids. If they refuse to pay the registration/stewardship fee we recommend a fine that has greater impact.
- Ensure public and private insurance programs cover the range of evidence-based pain treatments in a way that is accessible and affordable for patients

Addiction

- Facilitate referral of patients addicted to opioids to treatment programs
- Actively engage medical staff and hospital leadership in improving pain assessment and management, including strategies to decrease opioid use and minimize risks associated with opioid use
- Bring addiction treatment into the physician's offices. This will encourage more people to seek help. Goal is to treat patients in a primary care setting where they are already getting care, or in other less stigmatized settings outside of substance abuse clinics

Assessment and Management

- Improve pain assessment by concentrating more on how pain is affecting patients' physical function
- Develop definitions to recognize the difference between chronic pain and acute pain
  Consider the following exceptions: any patient who has a terminal prognosis; or any patient receiving

palliative care treatment for a life-threatening illness. These patients are not inherently at risk of addiction and their pain and symptom management should remain the priority.
- Develop evidence-based policy and practice on reasonableness of exceptions.
- Ensure prescribing practices can vary between chronic and acute pain

Non-pharmacological pain treatment modality

- Provide at least one non-pharmacological pain treatment modality

Monitoring and Reporting

- Require use of Rx monitoring program
- Provide funding to integrate the pain management plan (PMP) into electronic health record
- Create and maintain prescription drug monitoring programs that allow doctors and pharmacies to work together to curb misuse and abuse (including across state lines), while also helping to ensure care coordination

Dispensing and Controlling

- Develop safe unused pill disposals
- Create effective drug take-back programs that provide cancer and other patients with a safe way to dispose of unused medication

Research

- Fund federal research to develop new evidence-based pain treatments, pharmacological and non-pharmacological

2019 Palliative Care Advisory Council Impact Agenda

2019 Priorities

At the December 2018 meeting, the Council Chair named three priorities for planning for 2019. The Council anticipates it will:

1. Refine (work group policy) recommendations based upon stakeholder engagement
2. Identify gaps and new ideas
3. Develop strategy for engaging the legislature

Considerations for a Palliative Care State Plan

In 2017, the Minnesota Department of Health (MDH) wrote a grant to the Center for Disease Control's (CDC) Comprehensive Cancer Control Funding. As part of this larger proposal, the department desired to align efforts with the forthcoming Council and put forth a deliverable around palliative care, with the specific project period objective to develop a palliative care state plan. A state plan, among many things, provides a platform for public and private sector action that aligns stakeholders around a common vision and set of objectives and strategies related to palliative care for Minnesota. Early in 2018, MDH proposed the idea of developing a palliative care state plan to the Council. MDH and the Council took considerable time to discuss whether and how the Council might contribute to the creation of a palliative care state plan. In May 2018, MDH commissioned a contractor to propose a framework to develop the state plan. This included an analysis of stakeholders, partners, process and timeline. The proposed framework represented a best-case scenario and upon further consideration, factors such as budget and staff time required a more streamlined development approach to move forward. MDH took great efforts to listen to the concerns of the Council who in the end did not wish to take a leadership role in the state plan development. After considering all factors, including the CDC's new funding restrictions and requirements, MDH has put leadership for the development of a state plan on hold indefinitely.

Appendix A: Palliative Care Advisory Council Members

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
Physician certified by American Board of Hospice and Palliative Care Medicine
1. Julie Mayers Benson, MD Physician, Lakewood Health Systems; Associate Professor of Medicine, University of Minnesota Medical School Additional affiliations/experience: Board Certification, Hospice & Palliative Medicine Member, Lakewood Health System Hospice and Homecare Board Board President, MNHPC -Numerous presentations/publication related to palliative medicine -Current and 20+ year-long practitioner of primary and palliative care in rural central Minnesota -Developed the palliative care program at Lakewood Health System
Physician
2. Kirstin LeSage, MD Medical Director, Essentia Health Supportive and Palliative Care Additional affiliations/experience: American Academy of Hospice and Palliative Medicine Center to Advance of Palliative Care (CAPC) National Hospice and Palliative Care Organization Minnesota Network of Hospice and Palliative Care -Published research related to palliative medicine

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
-Numerous presentations related to palliative medicine -Membership of numerous palliative medicine-related committees, boards, and leadership seats
Registered Nurse certified by National Board for Certification of Hospice & Palliative Care Nurses
3. Joan "Jody" Chrastek, RN, DNP, CHPN, FPCN Pediatric Palliative Care Coordinator, Fairview Home Care and Hospice University of Minnesota Masonic Children's Hospital Additional affiliations/experience: National Hospice and Palliative Care Organization Pediatric Advisory Group International Work Group on Death, Dying and Bereavement -Co-Chair of the Pediatric Palliative Care Coalition of Minnesota, working for many years to promote education and access to pediatric palliative care in rural areas especially. -Currently serving as the Coordinator of the Pediatric Advanced Complex Care Team for Fairview Home Care and Hospice -Doctorate work focused on pediatric palliative care; nationally and internationally published and asked to present on palliative and hospice care.
Registered Nurse
4. Rebecca Weber, RN, APRN-BC, CPM, CRRN Certified Nurse Practitioner, Palliative Care HealthEast Care System Additional affiliations/experience: American Nurses Association/Minnesota Nurses Association American Academy of Hospice and Palliative Care National Hospice and Palliative Care Organization

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
Care Providers of Minnesota American Academy of Pain Physicians American Association of Rehabilitation Nurses Honoring Choices Ambassador -Sat for the Certification Hospice Palliative Care Nurse exam in September [2017]. -Experience as a Certified Nurse Practitioner in Palliative Care at acute care hospitals as well as in a hospice and palliative care setting -Expertise in rehabilitation and pain management
Care Coordinator
5. Patrice Moore, RN, OCN, BSN Clinical Care Coordinator, Fairview Ridges Cancer and Infusion Clinic Additional affiliations/experience: Oncology Nursing Society -First-hand view of the ways in which Palliative Care can alleviate the psychological, emotional and even physical turmoil of having a life-threatening or terminal illness -18 years' experience as Navy Nurse Corps Officer -Numerous years' experience as a Hospice Clinical Nurse Supervisor
Spiritual Counselor
6. Elizabeth Mahan, D.Min., M.Div., MBA Staff Chaplain, HealthEast Hospice

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
Additional affiliations/experience: Board Certified Chaplain, Association of Professional Chaplains Ordained Minister, United Church of Christ Ecclesiastical Endorsed Minister for Health Care Chaplaincy, United Church of Christ Facilitator and Instructor, Honoring Choices of Minnesota for Advance Care Planning Certified in Animal Assisted Therapy, Pet Partners. HTI Healing Touch Programs 1, 2, and 3. -Current position involves providing palliative and end of life care for hospice patients, families, and caregivers. -Many years of experience in this capacity: over 25 years of professional and academic experience in hospitals, hospices, long-term care centers, assisted living facilities, and oncology clinics. Experience serving urban, suburban, and rural areas in Minnesota.
Licensed Health Professionals
7. Mark Burnett, MT-BC Music Therapist, University of Minnesota Masonic Children's Hospital/Fairview Hospital Children's Hospitals and Clinics of Minnesota Private Practice Additional affiliations/experience: American Music Therapy Association Minnesota Music Therapy Association National Hospice and Palliative Care Organizations -Working on a collaborative project between Children's Hospitals and clinics of Minnesota, Gillette Children's, and the U of M Masonic Children's Hospital developing music therapy referral resources for children that are discharged to home locations in rural MN -Specialized in Pain, Palliative, and Hospice
8. Adine Stokes, LSW, BS

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
Advance Care Planning Facilitator North Memorial Medical Center, Robbinsdale Additional affiliations/experience (selected): Minnesota Board of Social Work 17 years' experience in aging services Currently employed on a Palliative Care Team as an Advance Care Planning Social Worker
9. Ginger Thompson Staff Pharmacist, Mayo Additional affiliations/experience: National Hospice Organization, Mayo Hospice Hospice Minnesota, Mayo Hospice Licensed Pharmacist, States of Minnesota and Iowa -Committed to personal and professional excellence in palliative care. Membership in numerous palliative and hospice medicine-related organizations. -Numerous publications and presentations related to palliative and hospice medicine.
Licensed Social Worker
10. Malinda Wise, BSW, MSW, LICSW Social Worker/Case Manager Mayo Clinic Additional affiliations/experience: National Hospice and Palliative Care Organization Mayo Clinic Hospice Advisory Committee

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
-Many years of experience as a clinical social worker and as a member of palliative care-related associations. -Since 2003, has worked within the Mayo Clinic system as a Hospice Program social worker, serving patients who are living with a terminal disease process.
Caregivers ***Note: This category is "Patients and Caregivers," but no patients were appointed to the Council in 2017.***
11. **Jessica Hausauer**, MA (PhD Candidate in Sociology) Program Director, MNHPC Adjunct Professor, Syracuse University Additional affiliations/experience: MN Leadership Council on Aging -- MNHPC Delegate Center to Advance Palliative Care National Hospice and Palliative Care Organization Minnesota Palliative Care Coalition Minnesota Gerontological Society Minnesota Emerging Leaders in Aging Network Hospice of the Twin Cities--Patient and Family Care Volunteer -Personal experience as caretaker to family member who did not receive adequate care at end of life
12. Deborah Laxson Owner and Founder, DayJoy, LLC Health Care Agent Literacy Project 7th Light Energy Therapy

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
Additional affiliations/experience: Member, MNHPC Member, Project Management Institute Member, Healing Beyond Borders -Personal experience implementing husband's end-of-life wishes and dealing with the consequences following. -Because of her experience doing this, wrote the book "The Gray Zone: When Life Support No Longer Supports Life" and founded the Health Care Agent Literacy Project in 2014 with the goal of preparing health care agents for their role in their loved one's life.
13. Carol Shapiro Speaker and advocate Additional affiliations/experience: Member, speaker, advocate: Alzheimer's Advocacy Forum Alzheimer's Association, MN/ND Alzheimer's Disease Working Group ACT on Alzheimer's Leadership Council, Steering Committee, Caregiver Leadership Group Twin Cities Jewish Community Alzheimer's Task Force Dementia Friends Champion Keeping the Spirit Alive Caregiver Conference DIAN Family Conference -Personal experience as wife of a person with young-onset Alzheimer’s
14. Dannell Shu Parent advocate, educator, mother, speaker, blogger Additional affiliations/experience:

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
End of Life Nursing Consortium Training Sessions on Palliative and Hospice Care Center to Advance Palliative Care podcast collaboration Children's Hospital and Clinics of MN training video on pediatric palliative care -Personal experience in palliative medicine as a mother to a child with significant brain damage and medical complexities. Son received palliative care and throughout the years, she was trained to lead an in-home ICU, significantly reduced ER visits and hospitalization
Representative from Health Plan
15. Howard Epstein, MD Senior Vice President & Chief Medical Officer PreferredOne Additional affiliations/experience): Board Certification, Internal Medicine/Hospice & Palliative Medicine Board of Directors, Society of Hospital Medicine Board of Directors, Minnesota Council of Health Plans Member, Honoring Choices Minnesota Advisory Council Co-Chair, Measurement and Reporting Committee, Minnesota Community Measurement -Developed initial business pro forma for new inpatient Palliative Care program, securing financial and admin support from hospital senior leadership -Led team that was first in the nation to receive Advanced Certification for Palliative Care Programs by the Joint Commission (Regions Hospital) -Career-long devotion to the promotion of quality, effective care
Physician Assistant member of American Academy of Hospice and Palliative Care Medicine
16. Ryan Baldeo, MPAS (Master of Physician Assistant Studies)

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
Anticipated 2019: Master of Science in Palliative Care Physician Assistant, Mayo Clinic Health Systems, Palliative Medicine Additional affiliations/experience: National Commission on Certification of Physician Assistant Liaison, Physician Assistants in Hospice and Palliative Medicine Member, MN Academy of Physician Assistants Chair of PA-C Special Interest Group, American Academy of Hospice and Palliative Medicine Member, American Academy of Physician Assistants Physician Assistant Representative, National Consensus Project; National Coalition of Hospice and Palliative Care Children's Grief Camp Counselor, Camp Oz
Members at Large
17. Karen Gervais, PhD Visiting Professor, St. Olaf College Director, Minnesota Center for Health Care Ethics Consultant Additional affiliations/experience: Member, Minnesota Commission on End-of-Life Care MDH Task Force on Health and Bioterrorism Co-Leader, Minnesota Pandemic Ethics Project Co-Director, community-wide ethics project on rationing health care resources in a severe pandemic -Ethics and policy consultant for numerous organizations relating to death, dying, and hospice/palliative medicine -Numerous publications and presentations related to palliative and hospice medicine
18. Karen Wald, MS, BS, CCC-SLP

Minnesota Palliative Care Advisory Council (PCAC) – Members Appointed in 2017
(Certificate of Clinical Competence, Speech Language Pathology) Regions Hospital Additional affiliations/experience: Minnesota Speech-Language Registration American Speech-Language-Hearing Association Twin Cities Clinical Speech-Language Pathologists -Experience working closely with the Palliative Care team at Regions Hospital as well as various community hospice team care providers. -Recognized as a strong advocate for the needs of her patients, providing compassionate care to patients managing complex conditions. -Completed the Honoring Choices Minnesota Advance Care Planning Facilitator Training
Student Designee (additional category)
19. Joy Liu, BS (MD expected in 2020) Current medical student at Mayo Clinic School of Medicine Previous: Lien Center for Palliative Care Additional affiliations: -Interested in bringing background and research experiences in palliative care to an advisory role [on PCAC], especially perspective from seeing palliative care in other states and countries. -Experience in and witness to palliative care in many roles from volunteer, to research assistance, to medical school. -Experience in and witness to advance care planning in Singapore.

Appendix B: PCAC By-Laws

Minnesota Palliative Care Advisory Council Bylaws

Approved 3/14/18

I. Name

The name of the council shall be the Minnesota Palliative Care Advisory Council (PCAC).

II. Introduction

The PCAC was created by the Minnesota Legislature according to Minnesota Statute Section 144.509.

III. Purpose

Consistent with Minnesota Statute Section 144.509, the purpose of the PCAC is to ensure that all Minnesotans who may benefit from palliative care are able to access those services.

IV. Duties of the PCAC

- *Consult and Advise.*

The PCAC shall consult with and advise the Commissioner of Health on matters related to the establishment, maintenance, operation, and outcomes evaluation of palliative care initiatives in the state.

- *Reporting.*

By February 15 of each year, the council shall submit to the chairs and ranking minority members of the committees of the senate and the house of representatives with primary jurisdiction over health care a report containing:

a. the PCAC's assessment of the availability of palliative care in the state;

b. the PCAC's analysis of barriers to greater access to palliative care; and

c. recommendations for legislative action, with draft legislation to implement the recommendations.

The Department of Health shall publish the report each year on the department's Web site.

V. Council Membership

1. Public Members.

- *According to Minnesota Statute 144.509, there will be 18 public members (members):*
    - 2 physicians, one who is certified by the American Board of Hospice and Palliative Medicine
    - 2 registered nurses or advance practice registered nurse, one who certified by the National Board for Certification of Hospice and Palliative Care nurses;
    - 1 care coordinator experienced in working with people with serious or chronic illness and their families;
    - 1 spiritual counselor experienced in working with people with serious or chronic illness and their families;
    - 3 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;
    - 1 licensed social worker experienced in working with people with serious or chronic illness and their families
    - 4 patients or caregivers experienced in working with people with serious or chronic illness
    - 1 representative from a health plan company
    - 1 physician assistant member of the American Academy of Hospice and Palliative Care Medicine
    - 2 members from the above categories.
- Members serve without compensation or reimbursement of expenses

2. Additional skills and qualifications.

a. Council membership must include, where possible, representation that is racially, culturally, linguistically, geographically, and economically diverse.
b. 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.
c. 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, and palliative care services for veterans as a provider or recipient, or pediatric care.
d. 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.
e. Optional members may include a medical student and lawyer.

3. Appointment by the Commissioner of Health.

Initial PCAC membership was determined through an application process, review by an external team, and appointment by the Commissioner of Health. From here forward, members will serve an initial 3-year term and may be reappointed. Members will serve until a replacement is named. The Commissioner of Health will appoint future members.

4. *Member responsibilities.*

Members of the PCAC have the following responsibilities:

a. Regular attendance at PCAC meetings
b. Work on PCAC projects, committees and work group
c. Maintain qualifications

5. *Membership Committee*

The membership committee is responsible for ensuring council vacancy recruitment, review and recommendations are made to the Commissioner of Health in a timely fashion. Furthermore, this committee will ensure members fulfillment of their responsibilities as outlined above and will review and make recommendations for dismissal as necessary.

6. *Terms*

Members of the council shall serve for three years and may be reappointed. Members serve until their successors have been appointed.

VI. Meetings of the PCAC

1. *General meetings.*

The PCAC will meet in person or by teleconference at least twice annually. The meetings will be open to members of the public in compliance with the open meeting law.

2. *Other meetings.*

Additional meetings including work group meetings may be called by the PCAC chair, vice chair, or work group leader**.**

3. *Meeting leadership.*

The PCAC chair, vice chair or designee will lead general meetings. Work group chairs will lead work group meetings.

4. *Meeting notice.*

Notice of meetings (date, time, and location) will be provided by the PCAC chair, vice chair, or MDH liaison to members at least 15 days prior to the meeting. Notice will be provided electronically at the address provided by the member. The agenda will be distributed no later than 3 days prior to the meeting. Minutes will be recorded, filed, and distributed to members by the PCAC chair, vice chair, or MDH liaison. The agenda and minutes will be posted on the MDH website with open access in compliance with the open meeting law.

5. *Quorum.*

A quorum for PCAC meeting shall be representation in person or virtually by 50% plus 1.

6. Voting.

Each member shall have one vote. Matters shall be decided by the vote of a majority of the members present at a meeting for which there is a quorum.

VII. Elected Positions

1. Elections.

The PCAC will elect its chair and vice chair at the first meeting of the PCAC and biannually thereafter. PCAC members interested in running for the vacant position will indicate their intention to run. PCAC members will vote during a general meeting.

2. Terms.

The chair and vice chair will serve a two year term of office. They will serve until a successor is elected. The chair and vice chair are eligible to run for re-election.

3. Chair

The PCAC chair will provide leadership to the PCAC with the support of the vice chair. The chair's responsibilities include the following:

a. Facilitate/moderate the meeting
b. Assure all items on agenda are addressed
c. Assure all members are heard and have their concerns addressed
d. Move the meeting along in a timely manner
e. Facilitate the council in such a manner to assure the duties of the council are being carried out

4. Vice chair.

The PCAC vice chair will support the chair in an as needed basis. The vice chair will lead meetings at which the chair is not present. The vice chair will participate in general meetings and contribute to its agenda.

5. Termination.

The PCAC may choose to terminate the chair or vice-chair by majority vote.

6. Vacancy.

A vacancy in the chair or vice chair positions prior to the conclusion of the term of office will be filled by a vote of the PCAC. The newly elected chair or vice chair will begin their term of service at the time of election.

VIII. Work Groups

1. *Establishment.*

The PCAC can establish work groups or other teams as it deems necessary to accomplish its duties. The establishment of a work group may be proposed by any PCAC member and put forward for a vote at a general meeting by the chair. Work groups may draw on the expertise of non-council members.

2. *Termination.*

Work groups or other teams may be terminated following the completion of their task or if no longer needed.

3. *Recommendations.*

Any recommendations, reports and/or products developed by such groups that are outside of the committee's delegated authority will be submitted to the general PCAC for approval prior to dissemination.

IX. Conflict of Interest

1. *Declaration.*

On any matter brought to a vote of the PCAC, members with a personal or organizational financial conflict of interest between the interests of the PCAC and the individual or member or other organization will be responsible to declare such conflict. Members shall complete and sign a conflict of interest form annually.

2. *Vote.*

The chair and/or vice chair will decide whether the PCAC should vote on the issue about which the conflict has been declared.

X. Amendments to the Bylaws

Amendment process.

The bylaws will be adopted and may be amended at a general meeting of members by majority vote. They will be reviewed bi-annually.

XI. Role of State Comprehensive Cancer Control Program Staff

Responsibilities.

The State Comprehensive Cancer Control Program staff/MDH liaison will have the following responsibilities within the PCAC:

General meetings – Attend general meeting. Attend other or work group meetings as necessary.

Operational and technical support – Provide administrative support necessary to facilitate the effective operation of the PCAC, ensure the completion of an annual legislative report, and act as a liaison with the Commissioner of Health

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