2022 PREVALENCE OF PALLIATIVE CARE IN MAINE STUDY

Brief Study by Hospice Analytics for
The Maine Hospice Council

v. 4/20/23

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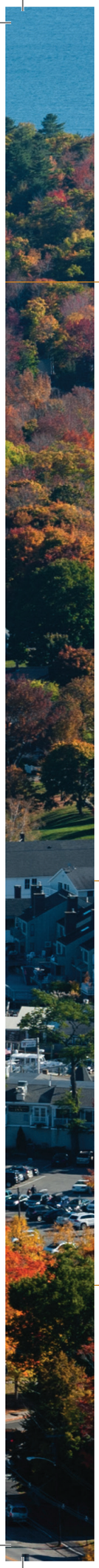

SUMMARY

In 2022, The Maine Hospice Council contracted with Hospice Analytics, Inc., to complete a phone survey of all Maine hospitals, hospices, and community providers regarding the provision of palliative care in 2021. This survey was a modified version of a similar study conducted by the Maine Hospice Council and Hospice Analytics in 2016. **In 2022, Hospice Analytics contacted 38 hospitals, 23 hospices, and 9 community-based providers across the state of Maine. Of these providers, 15/38 hospitals (39%), 4/23 hospices (17%), and 2/9 community-based providers (22%) had PC programs in 2021.**

In 2022, a total of 70 Maine providers were contacted. Of these 70 Maine providers, 21 palliative care providers were identified and completed surveys, compared to a total of 17 palliative care providers identified in the 2016 study.

KEY FINDINGS

HOSPITAL-BASED PALLIATIVE CARE PROGRAMS

1. **All 38 hospitals across the state of Maine were contacted in 2022.**
   Of these, 15 (39%) had palliative care (PC) programs. Of the 15 hospital-based PC programs, 10 met the Maine Hospice Council's definition of PC and five (5) were considered "modified" PC programs (meaning they met some, but not all, of the PC definition). This compares to 10/34 (29%) hospitals having PC programs in 2016. For the remainder of Maine hospitals: 22 hospitals reported no PC programs and one (1) hospital declined to participate in the survey.
2. **In 2022, the 15 Maine hospitals having PC programs tracked PC consultations and patients differently.**
   a. Eight (8/15, 53%) hospitals tracked patient consultations / encounters= 18,982 (mean= 2,373; range= 460-6,912).
   b. Four (4/15, 27%) hospitals tracked unduplicated patients / initial encounters only= 3,851 (mean- 963; range= 96-1,732).
   c. Two (2/15, 13%) hospitals tracked both consultations and unduplicated patients.
   d. Four (4/15, 27%) hospitals did not track consultations nor unduplicated patients.
   e. One (1/15, 6%) hospital contracted with a hospice for PC – this hospital's PC numbers are reported under the contracted hospice's totals.

   By comparison, in 2016 the total number of patients in Maine receiving hospital-based PC services was 4,554 (mean= 455; range= 20-1,483).
3. **Of the 15 hospital-based PC programs,** nine (9/15, 60%; 2016= 80%) billed for PC services.
4. **Of the 15 hospital-based PC program**s, 11 (11/15, 73%; 2016= 100%) utilized at least one physician and 8 (8/15, 53%; 2016= 70%) utilized at least one Nurse Practitioner.
5. **Of the 15 hospital-based PC programs,** 10 (10/15, 66%; 2016= 100%) utilized Social Workers.

HOSPICE-BASED PALLIATIVE CARE PROGRAMS

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5. **Of the 15 hospital-based PC programs,** 10 (10/15, 66%; 2016= 100%) utilized Social Workers.

COMMUNITY-BASED PALLIATIVE CARE PROGRAMS

1. **Nine (9) community-based providers in Maine were contacted in 2022** regarding the provision of PC. Of these, two (2/9, 22%) had PC programs. Of the two (2) programs, one (1/2, 50%) met the Maine Hospice Council's definition of PC and one (1/2, 50%) was considered a "modified" PC program (meaning they met some, but not all, of the PC definition). In 2016, four community-based providers representing multiple agencies were contacted, however none were found to meet the Maine definition for a PC program. For the remainder of Maine community-based providers: five (5) reported no PC programs and two (2) declined to participate in the survey.
2. **In 2022, of the two (2) Maine community-based providers having PC programs,** only one (1/2, 50%) tracked PC consultations and patients. This provider reported serving 65 unduplicated patients for 130 consultations/visits.
3. **Of the two (2) community-based PC programs,** one (1/2, 50%) billed for PC services.
4. **Of the two (2) community-based PC programs,** 1 (1/2, 50%) utilized at least one physician and 1 (1/2, 50%) utilized at least one Nurse Practitioner.
5. **Of the two (2) community-based PC programs,** one (1/2, 50%) utilized Social Workers.

KEY COMPARISONS

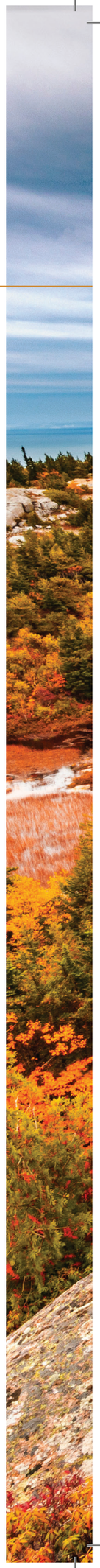
of Hospital-Based, Hospice-Based, and Community-Based Palliative Care Programs in Maine

KEY COMPARISONS	HOSPITAL-BASED		HOSPICE-BASED		COMMUNITY-BASED		TOTAL	
	2016	2022	2016	2022	2016	2022	2016	2022
Number of palliative care programs	10/34 (29%)	15/38 (39%)	7/26 (26%)	4/23 (17%)	0	2	17	21
Number of palliative care patients served	4,554 10 providers	3,851 4 providers	410 7 providers	20 1 provider	NA	65 1 provider	4,964 17 providers	3,936 6 providers
Number of palliative care consults/visits	NA	18,982 8 providers	NA	3,833 2 providers	NA	130 1 provider	NA	22,945 11 providers
Number of programs billing for palliative care	8/10 (80%)	9/15 (60%)	4/7 (57%)	3/4 (75%)	NA	1/2 (50%)	12	13
Number of programs utilizing at least 1 Physician	10/10 (100%)	11/15 (73%)	5/7 (71%)	3/4 (75%)	NA	1/2 (50%)	15	15
Number of programs utilizing at least 1 Nurse Practitioner	7/10 (70%)	8/15 (53%)	3/7 (42%)	2/4 (50%)	NA	1/2 (50%)	10	11
Number of programs utilizing at least 1 Social Worker	10/10 (100%)	10/15 (66%)	7/7 (100%)	2/4 (50%)	NA	1/2 (50%)	17	13

Notes: In 2016, PC programs either met the full definition or not (i.e., "modified" was not an option) and only the number of PC patients was asked (i.e., the of number of consults / visits receiving PC services was not asked).

BACKGROUND

In 2021, the Maine Hospice Council received a grant from the Maine Health Access Foundation to continue the study of PC across the state. Hospice Analytics contacted all Maine PC providers in 2022 (using calendar year 2021 data). This replicates and updates a similar project conducted in 2016 (using calendar year 2015 data) to collect baseline data about PC in the state of Maine. Data from the 2016 study was used to identify gaps, create a workplan, and initiate policy recommendations to the legislature regarding provision of PC services throughout the state. **The 2022 study examines changes in the provision of PC across the state of Maine since 2016.** The Maine Hospice Council contracted with Hospice Analytics, Inc., a Colorado-based research and consulting company, to design and administer phone surveys about PC with all the hospitals and hospices in Maine for both the 2016 and 2022 studies.



METHODS

From April through June of 2022, Cathy Wagner, RN, MSN, MBA, a researcher with Hospice Analytics, contacted all Maine hospitals, hospices, and community-based PC providers to conduct an extensive PC phone survey (Appendix 1). All responses were collected via live telephone conversation. A few respondents preferred completing the survey via email, with brief follow-up discussion. Several respondents provided estimates, noting they did not have the data available or the data was not collected in their organization. The Maine Hospice Council provided the following definition of PC which was used for this project.

The 2016 study only reported on PC programs meeting the full PC definition used for the study. The 2022 study also reports "modified" PC programs, acknowledging programs that provide some PC services, although not the full spectrum of services included in the definition.

***Palliative Care** means interdisciplinary, evidence-based, person-centered, family-focused medical care that optimizes quality of life by anticipating, preventing and treating suffering caused by a serious illness. This extra layer of support includes, but is not limited to, addressing physical, emotional, cultural, intellectual, and spiritual needs; facilitating and empowering individual autonomy and choice of care; honoring an individual's wishes; providing access to information; discussing the individual's goals of treatment and treatment options, including, when appropriate, Hospice Care; and managing pain and symptoms comprehensively. This care is provided and supported across the entire age spectrum.*

RESULTS

In 2022, Hospice Analytics contacted 38 hospitals, 23 hospices, and 9 community-based providers across the state of Maine to complete a PC phone survey. Of these providers, 15/38 hospitals (39%), 4/23 hospices (17%), and 2/9 community-based providers (22%) had PC programs in 2021. In 2022, a total of 70 Maine providers were contacted. Of these 70 Maine providers, 21 PC providers were identified and completed surveys, compared to a total of 17 PC providers identified in the 2016 study.

For those reporting having a PC program, telephone surveys took approximately 30 minutes to complete. For those reporting no PC program, telephone surveys took approximately 10 minutes to complete. The most challenging aspect of this project was identifying and setting an appointment with the correct person to complete the survey, which often involved multiple phone calls, sometimes taking longer than the actual survey administration.

HOSPITAL-BASED
PALLIATIVE CARE PROGRAMS

Thirty-eight (38) hospitals across the state of Maine were contacted to participate in the survey, including one Veterans Administration Hospital. One (1) of these hospitals declined to participate in the survey. Based on phone surveys, 10 (10/38; 26%) had PC programs meeting the PC definition used for this study and five (5/38; 13%) had "modified" PC programs – totaling 15 Hospital-Based PC Programs (15/38; 39%).

METRIC	2016	2022
Number of hospitals surveyed	**34**	**38**
Number (%) of hospices providing palliative care services:		
- Meeting full PC definition	10 (29%)	10 (26)%
- Meeting partial PC definition ("modified")	N/A	5 (13)%
Total	**10 (29%)**	**15 (39%)**
Number of patients receiving palliative care services:		
- PC Programs	10	4
- Sum	4,554	3,851
- Mean	455	963
- Range	20-1,483	96-1,732
Number of palliative care consultations/encounters:		
- PC Programs	N/A	11
- Sum	N/A	18,982
- Mean	N/A	2,373
- Range	N/A	460-6,912

Note: In 2016, PC programs either met the full definition or not – "modified" was not an option.

Two hospitals (2/15; 13%) tracked numbers of both unduplicated patients and consultations / encounters. Tracking numbers of both unduplicated patients and consultations / encounters is recommended as a best practice for all PC programs.

One hospital (1/15, 7%) reported serving pediatric PC patients.

HOSPITAL-BASED PALLIATIVE CARE TEAM COMPOSITION

DEDICATED, NON-DEDICATED, VOLUNTEER AND CONTRACTUAL STAFF	2016	2022
Physician, Intern, Resident, and/or Fellow	10/10 (100%)	11/15 (73%)
Advanced Practice Nurse / Nurse Practitioner	7/10 (70%)	8/15 (53%)
Registered Nurse	3/10 (30%)	6/15 (40%)
Social Worker	10/10 (100%)	10/15 (66%)
Chaplain	9/10 (90%)	7/15 (47%)
Certified Nurse Assistant	1/10 (10%)	3/15 (20%)
Pharmacist*	2/10 (20%)	2/15 (13%)
Psychologist*	1/10 (10%)	1/15 (7%)
Office Manager / Administrative Assistant*	1/10 (10%)	2/15 (13%)
Dietician*	1/10 (10%)	2/15 (13%)
Physician Assistant*	1/10 (10%)	2/1 (13%)
Volunteers (in a non-professional role)*	0	0

HOSPITAL-BASED PALLIATIVE CARE PROGRAM DESCRIPTIONS

Established: The first hospital-based PC program In Maine was established in 2001. The most recent was established in 2022.

Certification – Staff: In 2022, seven (7/15, 47%; 2016= 70%) of hospital-based PC programs had at least one physician certified in Hospice and Palliative Medicine. Six (6/15, 40%; 2016= 40%) programs had at least one certified Nurse Practitioner and one (1/15, 7%; 2016= 20%) had at least one Registered Nurse certified in Hospice and Palliative Care. Additionally, two (2/15, 13%; 2016= 10%) programs had certified Social Workers.

Certification – Program: None (0/15, 0%; 2016= 0%) of the hospital-based PC programs were certified in PC by third party accreditation organizations (i.e., Joint Commission, CHAP, ACHC, or DNV GL).

HOSPITAL-BASED PALLIATIVE CARE PROGRAMS

Operating hours: None (0/15, 0%; 2016= 40%) of the hospital-based PC programs offered PC services 24/7/365.

Services: All PC teams reported providing predominantly symptom management and discussions around goals of care. Other respondents added that their programs also provide: advance care planning, POLST discussions, resource management, patient placement, community resources, and PC fellowship programs.

Locations: The most common location for PC services among hospital-based programs was the inpatient hospital setting (~75%), followed by outpatient clinics (~20%) and community-based locations (~5%). One (1/15, 7%) hospital-based PC program reported providing home-based PC.

Race: Mostly consistent with Maine demographics, 10 (10/15, 67%) hospital-based PC programs reported ~97% (3% minority) of PC staff were White serving ~94% (6% minority) White patients.

Telehealth: Ten (10/15, 67%) hospital-based PC programs reported a mean 14% of consults / visits occurring via telehealth.

Integrative / Alternative Therapies: Two (2/15, 13%) of hospital-based PC programs included occasional osteopathic manipulations by osteopathic physicians and one (1/15, 7%) program noted inclusion of reiki practices.

POLST: POLST (Physician Orders for Life Sustaining Treatment) was being used in 9/15 (60%) of the PC programs. Most of these programs indicated increased satisfaction with the POLST over the past five years, although two programs noted no change in satisfaction, and one suggested the POLST is best used outside of the hospital setting.

Advance Directives: Eleven (11/15, 73%) hospital-based PC programs reported a mean 34% of patients being admitted to their PC programs with a completed advance directive (e.g., Maine Healthcare Directive, 5 Wishes, etc.).

Patient Outcomes: Nine (9/15, 60%) of the hospital-based PC programs reported a mean of 39% of PC patients being discharged to hospice. Eight (8/15, 53%) of the hospital-based PC programs reported a mean of 25% of PC patients dying on PC service. This was consistent with 10 (10/15, 67%) of hospital-based PC programs serving an average of 70% of patients in late stage of illness (as opposed to early or mid-stage).

Diagnoses: The most commonly treated illnesses encountered by the PC team were cancer, dementia, cardiac and respiratory diseases. Less frequently encountered illnesses included sepsis, liver diseases, and Parkinson's Disease.

Symptoms: The most commonly treated symptoms included pain, shortness of breath, delirium, nausea, and existential suffering.

COVID-19: Twelve (10/15, 67%) hospital-based PC programs discussed various impacts COVID-19 had on their services. Some reported increased patient volume although decreased revenue, while others reported decreased patient volume with increased revenue. Several mentioned increased use of telehealth and increased completion of advance directives. Two (2/15, 13%) programs reported COVID-19 having no impact on their services.

REFERRALS

- **Most hospital-based respondents reported their primary referral sources for the PC program were hospitalists and intensivists.** Others referral sources included oncology, ER, cardiology, and varied nurses. The 2016 study reported similar referral sources.
- **In 2022, one (1/15, 7%; 2016= 50%) of program utilized automatic triggers which served to initiate a PC consult.** Triggers included patients receiving extracorporeal membrane oxygenation (ECMO) and a left ventricular assist device (LVAD). Two (2/15, 13%) programs had automatic triggers to recommend a PC consult. Triggers recommending a PC consult included: clinical frailty scores, terminal ventilator wean, and stage IV cancer diagnoses. Additionally, one (1/15, 7%) noted that they no longer used the "Surprise Question" ('Would you be surprised if this patient died within the next year?') as an automatic trigger for PC consults because it prompted too many inappropriate referrals.

FINANCIAL ASPECTS AND BILLING

- **In 2022, seven (7/15, 47%; 2016= 100%) hospital-based PC programs reported their administration financially prioritized the PC program.** Ten (10/15, 66%) respondents reported the need for greater financial support and additional staff to serve more patients.
- **Nine (9/15, 60%; 2016= 80%) of the hospitals billed for palliative services.** All nine reported billing Medicare as well as other payors (e.g., Medicaid, commercial payors, patients themselves, etc.). Respondents reported billing for PC services in a variety of ways: by physician, z codes, time, symptom codes, and diagnosis codes.
- **In 2022, six (6/15, 40%; 2016= 50%) hospitals used Z51.5 (ICD-10; ICD-9 used V66.7 for encounter for palliative care) codes** for tracking purposes in their PC programs.
- **When asked what percentage of program expenses were paid for by direct billing, responses averaged 60% (range= 40% - 90%).**
- **In 2022, three (3/15, 20%; 2016= 20%) PC programs collected and tracked statistics about how their PC program saved the hospital money or avoided costs.** Cost savings / cost avoidance was reported as: $2000 per day per PC patient; $2.3M savings in 2022; and $3.6M savings in 2020-2021. One program noted current cost savings are being calculated as part of a grant, although results are not yet available.

OUTCOME MEASURES

- **Eight (8/15, 53%) hospital-based PC programs collected statistics and outcome measures.** Those measures included patient satisfaction, hospital readmission rates, completion of advance directives, hospice referrals, length of stay, and timeliness of initial consult. In addition to these measures, the 2016 survey participants also collected: symptom scores, length of stay pre-and-post consult, costs, referral source, location of care, patient disposition, number of consults, reason for referral, type of intervention, and satisfaction survey from hospitalists.
- **Hospital-based respondents were asked, "Where has your program had the greatest impact for patients and families?"** The most frequently stated was about increased coordination of care through clarification of goals. Other comments included: better symptom management, better planning and understanding of the death process, increased hospice utilization, increased support by having a single point of contact, and lower hospital readmission rates.
- **Hospital-based respondents were asked, "Where has your program had the greatest impact for healthcare professionals?"** The most frequently stated impacts were tied between providing additional support for staff regarding symptom management and time savings because PC professionals take responsibility for difficult (and long) conversations with patients and families (regarding goals of care). Other comments included: better communication and decreased moral distress.
- **Hospital-based respondents were asked, "What are your greatest challenges?"** The most frequent responses were lack of finances and lack of staff. Two programs also mentioned a lack of data supporting PC services.

HOSPICE-BASED
PALLIATIVE CARE PROGRAMS

PREVALENCE OF HOSPICE-BASED PALLIATIVE CARE PROGRAMS

Twenty-three (23) hospices across the state of Maine were contacted. Based on 2022 phone surveys, three (3/23, 13%; 2016= 26%) reported having a PC program and one (1/23; 4%) had a "modified" PC program – totaling four Hospice-Based PC Programs (4/23; 17%).

METRIC	2016	2022
Number of hospices surveyed	**26**	**23**
Number (%) of hospices providing palliative care services:		
- **Meeting full PC definition**	7/26 (26%)	3/23 (13%)
- **Meeting partial PC definition ("modified")**	N/A	1/23 (4%)
Total	**7/26 (26%)**	**4/23 (17%)**
Number of patients receiving palliative care services:		
- **PC Programs**	7	1
- **Sum**	410	20
- **Mean**	58.5	20
- **Range**	0-150	20
Number of palliative care consultations/encounters:		
- **PC Programs**	N/A	2
- **Sum**	N/A	3,833
- **Mean**	N/A	1,917
- **Range**	N/A	1,637-2,196

Note: In 2016, PC programs either met the full definition or not – "modified" was not an option.

No hospices (0/4; 0%) tracked numbers of both unduplicated patients and consultations / encounters. *Tracking numbers of both unduplicated patients and consultations / encounters is recommended as a best practice for all PC programs.*

Two hospices (2/4, 50%) reported serving pediatric PC patients.

HOSPICE-BASED PALLIATIVE CARE TEAM COMPOSITION

Twenty-three (23) hospices across the state of Maine were contacted. Based on 2022 phone surveys, three (3/23, 13%; 2016= 26%) reported having a PC program and one (1/23; 4%) had a "modified" PC program – totaling four Hospice-Based PC Programs (4/23; 17%).

DEDICATED, NON-DEDICATED, VOLUNTEER AND CONTRACTUAL STAFF	2016	2022
Physician	5/7 (71%)	4/4 (100%)
Advanced Practice Nurse / Nurse Practitioner	3/7 (42%)	2/4 (50%)
Registered Nurse	6/7 (85%)	3/4 (75%)
Social Worker	7/7 (100%)	2/4 (50%)
Chaplain	5/7 (71%)	2/4 (50%)
Certified Nurse Assistant	3/7 (42%)	0
Pharmacist*	0	0
Psychologist*	0	0
Office Manager / Administrative Assistant*	0	0
Dietician*	0	0
Physician Assistant*	0	0
Volunteers (in a non-professional role)*	3/7 (42%)	0

**These disciplines were not specifically asked for, although often mentioned by providers with them.*

HOSPICE-BASED PALLIATIVE CARE PROGRAM DESCRIPTIONS

Established: The first hospice-based PC program In Maine was established in 2010. The most recent was established in 2020.

Certification – Staff: In 2022, all four (4/4, 100%; 2016= 57%) hospice-based PC programs had at least one physician certified in Hospice and Palliative Medicine. Two (2/4, 50%; 2016= 14%) programs had at least one certified Nurse Practitioner and two (2/4, 50%; 2016= 43%) had at least one Registered Nurse certified in Hospice and Palliative Care. No (0/4, 0%; 2016= 0%) programs had certified Social Workers. One (1/4, 25%; 2016= 14%) hospice had an Administrator Certified in Hospice and Palliative Care. The professional discipline of that administrator was unknown.

Certification – Program: None (0/4, 0%) of the hospice-based PC programs were certified in palliative care by third party accreditation organizations (i.e., Joint Commission, CHAP, or ACHC). This information was not asked in the 2016 survey.

Operating hours: None (0/4, 0%; 2016= 71%) of the hospice-based PC programs made patient visits 24/7/365. However, most had a mechanism in place to receive phone calls from patients 24/7/365.

Services: All hospice-based PC teams reported providing predominantly symptom management and discussions around goals of care. Other respondents added that their programs also provide community education, counseling, and resource navigation.

Locations: The most common location for PC services among hospice-based programs was the community. In fact, three (3/4, 75%) hospice-based PC providers reported 100% of PC services were provided in the community. One provider (1/4, 25%) reported 55% of PC services were provided in the hospital and 45% in the community.

Race: Mostly consistent with Maine demographics, four (4/4, 100%) hospice-based PC programs reported ~90% (10% minority) of PC staff were White serving ~90% (10% minority) White patients.

Telehealth: Two (2/4, 50%) hospice-based PC programs reported a mean 17% of consults / visits occurring via telehealth.

Integrative / Alternative Therapies: One (1/4, 25%) of the hospice-based PC programs included massage therapy and acupuncture.

POLST: POLST (Physician Orders for Life Sustaining Treatment) was being used in 4/4 (100%) of the hospice-based PC programs. All hospice-based PC programs indicated increased satisfaction with the POLST over the past five years.

Advance Directives: Two (2/4, 50%) hospice-based PC programs reported a mean 60% of patients being admitted to their PC programs with a completed advance directive (e.g., Maine Healthcare Directive, 5 Wishes, etc.).

Patient Outcomes: Four (4/4, 100%) of the hospice-based PC programs reported a mean 70% of PC patients being discharged to hospice. Two (2/4, 50%) of the hospice-based PC programs reported a mean 13% of PC patients dying on PC service. This is consistent with 4 (4/4, 100%) of hospice-based PC programs serving an average of 50% of patients in late stage of illness (as opposed to early or mid-stage).

Diagnoses: The most commonly treated illnesses encountered by the PC team were cancer, dementia, and cardio-respiratory diseases.

Symptoms: The most commonly treated symptoms treated included pain, shortness of breath, fatigue, and existential suffering.

COVID-19: All four (4/4, 100%) hospice-based PC programs discussed various impacts COVID-19 had on their services. One provider reported increased patient volume although decreased revenue, while another reported increased patient volume with increased revenue. One provider mentioned increased use of telehealth. One (1/4, 25%) program reported COVID-19 having no impact on their services.

REFERRALS

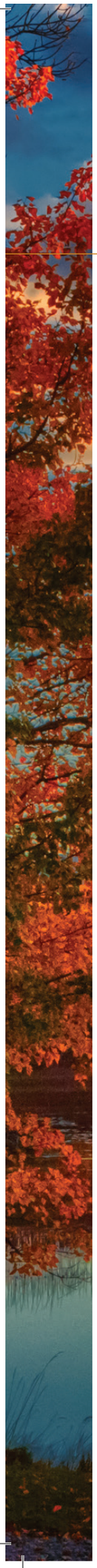
- **All four hospice-based PC programs (4/4, 100%) reported the majority of their PC referrals come from primary care providers.** Other referral sources included discharge-planners, oncologists, home health care personnel, and skilled nursing facility personnel.

FINANCIAL ASPECTS AND BILLING

- **All four hospice-based PC programs (4/4, 100%) reported their PC teams had strong administrative support for their program.** However, three (3/4, 75%) providers reported reported needing additional financial support.
- **Three (3/4, 75%) hospice-based PC providers billed for palliative services.** Payors billed include Medicare, Medicaid, commercial payors, private bill to patient, etc.
- **Three (3/4, 75%) hospice-based PC providers** used Z51.5 (ICD-10 encounter for palliative care) codes for tracking purposes in their PC programs.
- **When asked what percentage of program expenses were paid for by direct billing, responses averaged 20% (range= 10% - 30%).**

OUTCOME MEASURES

- **All four (4/4, 100%) hospice-based PC programs collected statistics and outcome measures.** Those measures included hospice referrals, patient and family satisfaction, referral sources, hospital readmissions, and completion of goals of care conversations and advance directives.
- **Hospice-based respondents were asked, "Where has your program had the greatest impact for patients and families?"** Responses included patient improved quality of life, care coordination, satisfaction with care, and reduced unnecessary hospitalizations.
- **Hospice-based respondents were asked, "Where has your program had the greatest impact for healthcare professionals?"** The most frequently stated impact regarded increased job satisfaction. Additional responses included improved symptom management, care coordination, and reduced unnecessary hospitalizations.
- **Hospice-based respondents were asked, "What are your greatest challenges?"** The most frequent responses were lack of finances and lack of staff. Additional responses included the need to increase education about PC in the lay and professional communities, electronic medical record difficulties, and data retrieval challenges.



COMMUNITY-BASED PALLIATIVE CARE PROGRAMS

PREVALENCE OF COMMUNITY-BASED PALLIATIVE CARE PROGRAMS

In 2022, nine (9) community-based providers were contacted about the provision of PC. Based on phone surveys, one (1/9, 11%; 2016= 0%) reported having a PC program meeting the PC definition used for this study and one (1/9, 11%) had a "modified" PC program – totaling two (2) Community-Based PC Programs (2/9; 22%). This is the first-time community-based PC providers have been identified in Maine.

METRIC	2016	2022
Number of community-based providers surveyed	**4**	**6**
Number (%) of community-based services providing palliative care services:		
- Meeting full PC definition	0	1/9 (11%)
- Meeting partial PC definition ("modified")	0	1/9 (11%)
Total	**0**	**2/9 (22%)**
Number of patients receiving palliative care services:		
- PC Programs	N/A	1
- Sum	N/A	65
- Mean	N/A	65
- Range	N/A	65
Number of palliative care consultations/encounters:		
- PC Programs	N/A	1
- Sum	N/A	130
- Mean	N/A	130
- Range	N/A	130

Note: In 2016, PC programs either met the full definition or not – "modified" was not an option.

One community-based PC provider (1/2; 50%) tracked numbers of both unduplicated patients and consultations / encounters. T*racking numbers of both unduplicated patients and consultations / encounters is recommended as a best practice for all PC programs.*

Neither community-based PC provider (0/2, 0%) reported serving pediatric PC patients.

COMMUNITY-BASED PALLIATIVE CARE TEAM COMPOSITION

DEDICATED, NON-DEDICATED, VOLUNTEER AND CONTRACTUAL STAFF	2016	2022
Physician	0	2/2 (100%)
Advanced Practice Nurse / Nurse Practitioner	0	1/2 (50%)
Registered Nurse	0	0
Social Worker	0	0
Chaplain	0	0
Certified Nurse Assistant	0	0
Pharmacist*	0	0
Psychologist*	0	0
Office Manager / Administrative Assistant*	0	0
Dietician*	0	0
Physician Assistant*	0	0
Volunteers (in a non-professional role)*	0	0

**These disciplines were not specifically asked for, although often mentioned by providers with them.*

COMMUNITY PALLIATIVE CARE PROGRAM DESCRIPTIONS

Established: The first and most recent community-based PC program in Maine was established in 2020.

Certification – Staff: Both (2/2, 100%) of the community-based PC programs had at least one physician certified in Hospice and Palliative Medicine. One (1/2, 50%) program had certified Social Workers. No (0/2, 0%) programs had certified Nurse Practitioners or Registered Nurses certified in Hospice and Palliative Care.

Certification – Program: None (0/2, 0%) of the community-based PC programs were certified in palliative care by third party accreditation organizations (i.e., Joint Commission, CHAP, or ACHC).

Operating hours: None (0/2, 0%) of the community-based PC programs offered PC services 24/7/365.

Services: In addition to symptom management and discussions around goals of care, community-based PC programs also provided Death with Dignity (medical aid in dying), community education, support groups, and an immunization clinic.

Locations: One (1/2, 50%) community-based PC provider reported 95% of services were provided in a physician outpatient clinic and 5% in the home. The other community-based provider reported the opposite – 85% of services were provided in the home, 10% in the hospital, and 5% in an outpatient clinic.

Race: Mostly consistent with Maine demographics, both (2/2, 100%) community-based PC programs reported 100% of PC staff were White serving 100% White patients.

Telehealth: One (1/2, 50%) community-based PC program reported 33% of consults / visits occurring via telehealth, the other reported 1%.

Integrative / Alternative Therapies: Neither (0/2, 0%) of the community-based PC programs included integrative / alternative therapies, although one provider mentioned patients could be referred to Integrative Specialists.

POLST: POLST (Physician Orders for Life Sustaining Treatment) was being used in 2/2 (100%) of the community-based PC programs. Both community-based PC programs indicated increased satisfaction with the POLST over the past five years.

Advance Directives: Both (2/2, 100%) of the community-based PC programs reported a mean 40% of patients being admitted to their PC programs with a completed advance directive (e.g., Maine Healthcare Directive, 5 Wishes, etc.).

Patient Outcomes: Both (2/2, 100%) of the community-based PC programs reported a mean 70% of PC patients being discharged to hospice. They reported a mean 5% of PC patients dying on PC service. This is consistent with both serving an average 50% of patients in late stage of illness (as opposed to early or mid-stage).

Diagnoses: The most commonly treated illnesses encountered by the PC team were dementia, cancer, respiratory diseases, and Parkinson's Disease.

Symptoms: The most commonly treated symptoms treated included anxiety, shortness of breath, anorexia, and depression.

COVID-19: Both (2/2, 100%) community-based PC programs reported the primary impact of COVID-19 was to increase demand for their services.

SUMMARY
& RECOMMENDATIONS

Palliative care is growing rapidly throughout the United States. This study has confirmed the number of palliative care providers in the state of Maine has increased since 2016 – including, for the first time, identifying community-based palliative care providers. This is a positive step towards better health, lower costs and higher quality of care across the state.

New in the 2022 study, we found it important to detail both the number of patients receiving palliative care as well as the number of palliative consultations / encounters that occurred. While we recommend palliative care providers collect and report numbers of both patients and consults, most providers collected and reported one or the other. A current directory of palliative care providers in Maine has been created (Appendix 2). Telephone calling each palliative care provider was an effective (albeit time consuming) way to capture the data.

Based on the survey process and analysis, we make the following recommendations:

1. **Ongoing palliative care education for both providers and the public continues to be needed – particularly regarding the definition of palliative care and how it is similar to / different from hospice care.** This will help increase knowledge and awareness of palliative care, and potentially lead to additional and earlier referrals to palliative care programs.
2. **Additional funding is needed for palliative care programs.** Lack of funding continues to be the most important priority for palliative care programs – specifically to hire more clinical, IT / data collection, and administrative staff. This impacts the mission and purpose of palliative care services – building and appropriately paying the professional workforce, workforce shortages, moral distress, etc.
3. **Additional education is needed for palliative care providers regarding the need for and how to collect and analyze consistent metrics.** For example, the importance of collecting and reporting both the numbers of PC patients served and the number of consultations / encounters they had; use of the Z51.5 ICD-10 code to track encounters with palliative care; cost savings / avoidance; consistent terminology (e.g., "consult" or "visit"); etc.
4. **Specialty palliative care certification for individuals and palliative care accreditation for programs is important in demonstrating an advanced level of knowledge and practice.** Certification and accreditation was relatively underrepresented in Maine.
5. **Telehealth in palliative care (and healthcare) has expanded during COVID-19.** Mechanisms are needed to ensure palliative care services and communication networks are available to accommodate this expansion statewide.
6. **Ongoing statewide education, networking, mentoring, practice standards, and advance care planning efforts need continued support.**
7. **There was some change in the survey reporting from 2016 to 2022 in the use and helpfulness of POLST (Physician Orders for Life Sustaining Treatment).** In the 2016 study, the majority of all palliative care providers reported using the POLST and finding it helpful. In the 2022 study, hospital-based palliative care providers reported decreased use and helpfulness of the POLST, while hospice-based and community-based palliative care providers continued to use the POLST and find it helpful. Exploring these divergent responses may uncover new opportunities to improve communication with patients.

8. **The 2022 study found no palliative care providers offering patient visits / consults 24/7/365 across hospitals, hospices, or community-based palliative care programs.** We recommend at least one palliative care provider offer palliative care services for their local community (as well as an off-hours resource for the entire state).
9. **All of healthcare is focusing on quality measures and transparency – palliative care providers must define and operationalize what measures will be most helpful for patients and providers.**
10. **Based on comments from several respondents, there continues to be a need for expanded palliative care services to reach rural areas.** Examining this issue and working toward resolution would be very beneficial to the rural community.
11. **For future surveys, it will be important to distinguish between a palliative care PROGRAM (as defined by Maine definition) vs. an INDIVIDUAL who provides care that is palliative in nature.** There may be more and more community-based providers, some even certified in Hospice and Palliative Care/Medicine, that provide excellent care to patients that is palliative in nature (comfort oriented, includes family, holistic, goals of care focused, etc.). But these individuals are not a PROGRAM of care. We need to decide if we want to capture data from the care they provide, or only capture data from the palliative care programs.
12. **It is important to repeat this survey of palliative care every 5 years in order to identify current palliative care providers and to measure the expansion of their palliative care programs.** This will help to identify gaps and plan for the future.

2022 MAINE
PALLIATIVE CARE PROGRAMS

A map of PC provider in listed in Appendix 2

APPENDIX 1

PREVALENCE OF PALLIATIVE CARE IN MAINE

Telephone Survey Questions
For Palliative Care provided in Calendar Year 2021
v. 3/14/22

The Maine Hospice Council provided the following definition of palliative care which was used for this project.

Palliative Care means interdisciplinary, evidence-based, person-centered, family-focused medical care that optimizes quality of life by anticipating, preventing and treating suffering caused by a serious illness. This extra layer of support includes, but is not limited to, addressing physical, emotional, cultural, intellectual, and spiritual needs; facilitating and empowering individual autonomy and choice of care; honoring an individual's wishes; providing access to information; discussing the individual's goals of treatment and treatment options, including, when appropriate, Hospice Care; and managing pain and symptoms comprehensively. This care is provided and supported across the entire age spectrum.

1. **Provider facility name and Contact(s) name/title, phone, email information.**
2. **Do you have a Palliative Care Program in place (separate from the Medicare Hospice Benefit)?**
    a. If no, to whom do you refer patients for this type of care?
    b. If no, do you plan to offer palliative care in the future?

    ----------If no palliative care program, STOP HERE----------

3. **When was your Palliative Care Program established, and when was your first patient served?**
4. **Current organization of your Palliative Care Program:**
    a. Describe where Palliative Care fits into your organizational structure.
    b. What disciplines participate in the program (e.g., physicians, nurses, social work, chaplain, etc.), and how many FTEs are represented by each?
    c. How many of your professional staff are Board Certified/Accredited in Hospice & Palliative Medicine/Care? (physician, RN, LPN/LVN, administrator, chaplain, social worker, pediatric nurse, APN, nursing assistant, perinatal loss counselor, death and bereavement counselor, pastoral psychotherapist or supervisor)

d. Where are services provided, and how many consultations / visits / patients are provided in each location – Inpatient, outpatient clinic, home/community based?

e. For hospitals: If you don't currently provide home-based palliative care, do you have plans to do so in the future?

f. Does your program provide patient visits in their place of residence 24/7/365?

g. Is your palliative care program (specifically and separately) certified/accredited by The Joint Commission, CHAP, ACHC, or DNV GL? If not, are you considering it?

5. Palliative Care Program patient services:

a. How many palliative care visits or consultations were completed in 2021, or patients seen- however your data is counted?

b. In addition to goals of care, symptom management, and ACP, what other services does your palliative care team currently provide?

c. Is POLST being used, and if so, has its utilization and satisfaction increased over the past 5 years?

d. What are the top 3 conditions or diagnoses you typically see patients present with?

e. What top 3 symptoms do you typically see patients present with?

f. Where do your current referrals typically come from?

   i. For hospitals: e.g., oncology, ICU, ED, etc.

   ii. For hospices: e.g., home health, oncologist, PCP, etc.

g. What disciplines most frequently identify the need for palliative care referrals (e.g., social work, physicians, nurses, etc.)?

h. What percentage of your palliative care patients are discharged:

   i. deceased?

   ii. to hospice?

   iii. other?

   iv. For hospitals: to outpatient / home-based palliative care?

i. What percentage of your current visits/consults are via technology as opposed to face-to-face (telehealth: including phone calls, video chats, etc.)?

j. Does your palliative care program include any integrative / alternative interventions (e.g., acupuncture, Reiki, massage therapy, etc.)? Please describe.

k. What percentage of your current patients are in an early stage of illness?

   i. Mid-stage?

   ii. Late stage?

l. How many pediatric patients did you serve in 2021?

m. What is the current racial composition of patients? Staff? (White, Black, Latino, Asian, etc.)?

6. **Financial aspects of your Palliative Care Program:**
    a. Does your administration financially prioritize palliative care? Please describe.
    b. Do you currently bill for palliative care services? If YES:
        i. Do you bill all payors (e.g., Medicare, Medicaid, commercial payors, private bill to patient, etc.)?
        ii. How do your providers capture information about the palliative care consults / visits in order for billing to occur? (V66.7 (ICD9) or Z51.5 (ICD10) code (encounter for palliative care), or perhaps a counseling code)
        iii. What percentage of your 2021 program expenses were paid by direct billing?
    c. How has COVID impacted your palliative care program revenue and services?
7. **Outcome measures for your Palliative Care Program:**
    a. What metrics does your program currently use to track success (e.g., patient satisfaction survey, hospice referrals, completion of advance directives, etc.)?
    b. Are you monitoring outcomes of your palliative care interventions for quality purposes? If yes, please describe.
    c. What percentage of patients admitted to your palliative care program have a completed advance directive (e.g., Maine Healthcare Directive, 5 Wishes, etc.)?
    d. Where has your program had the greatest impact:
        i. For patients and families?
        ii. For healthcare professionals?
    e. What are the greatest challenges in your palliative care program today?
8. **Hospitals only:**
    a. How many hospices does your program currently work with / refer to?
    b. Do your Discharge Planners receive education about palliative care during their initial employment orientation?
    c. How many in-services per year do you offer to hospital staff about palliative care?
    d. Are there automatic triggers in your EMR which initiate a palliative care consult (e.g., stage IV cancer, long ICU stay, presence of V66.7/Z51.5 codes outside of palliative care consult team)?
    e. Do you collect program data about cost savings / cost avoidance? If so, how much money does palliative care save the hospital each year?
9. **Hospitals and Hospices: Outside of your local hospitals and hospices, are there any other unique palliative care providers in your area?**
10. **Hospitals and Hospices: May we have your permission to share this survey information with interested state and national groups?**

APPENDIX 2

2022 DIRECTORY OF MAINE PALLIATIVE CARE PROVIDERS
(alphabetical by provider type)

HOSPITAL-BASED PALLIATIVE CARE PROGRAMS

HOSPITAL-BASED PALLIATIVE CARE PROGRAMS	# PALLIATIVE CARE PATIENTS SEEN IN 2021	# PALLIATIVE CARE CONSULTS IN 2021
BRIDGTON HOSPITAL 201310 (Central Maine Healthcare) Modified PC Program 10 HOSPITAL DRIVE, BRIDGTON, ME 04009 207-647-6000 Contact: Amy Dugas Phone: 207-647-6159	*	*
CENTRAL MAINE MEDICAL CENTER 200024 (Central Maine Healthcare) PC Program 300 MAIN STREET, LEWISTON, ME 04240 207-795-0111 Contact: Dr. Bruce Condit Email: conditbr@cmhc.org Phone: 207-795-7575	723	3,027
CHARLES A DEAN MEMORIAL HOSPITAL (CAH) 201301 (Nrthrn Light) PC Program PRITHAM AVENUE PO BOX 1129, GREENVILLE, ME 04441 207-695-5200 Contact: Dr. Joseph (Joe) Babbitt Email: joe.babbitt@northernlight.org Phone: 207-695-5256	*	*
MAINE MEDICAL CENTER 200009 (Maine Health) PC Program 22 BRAMHALL ST, PORTLAND, ME 04102 207-662-0111 Contact: Laura Seeger Email: laura.seeger@mainehealth.org Phone: 207-662-5598	1,732	6,912
MAINEGENERAL MEDICAL CENTER 200039 PC Program 35 MEDICAL CENTER PARKWAY, AUGUSTA, ME 04330 207-872-1000 Contact: Dr. Robert Dohner Email: robert.dohner@mainegeneral.org Phone: 207-626-1157	*	3,814

HOSPITAL-BASED PALLIATIVE CARE PROGRAMS	# PALLIATIVE CARE PATIENTS SEEN IN 2021	# PALLIATIVE CARE CONSULTS IN 2021
MID COAST HOSPITAL/MID COAST PARKVIEW HEALTH 200021 (Maine Health) PC Program 123 MEDICAL CENTER DRIVE, BRUNSWICK, ME 04011 207-729-0181 Contact: Dr. David Dumont Email: david.dumont@mainehealth.org Phone: 207-721-1201	1,300	*
MOUNT DESERT ISLAND HOSPITAL 201304 (CAH) PC Program 10 WAYMAN LANE PO BOX 8, BAR HARBOR, ME 04609 207-288-5081 Contact: Heather Sinclair Email: heather.sinclair@mdihospital.org Phone: 207-801-5064	96	*
NORTHERN LIGHT A R GOULD HOSPITAL 200018 (Was Aroostook Medical Center and has same ID/ address) Modified PC Program PO BOX 151, PRESQUE ISLE, ME 04769 207-768-4000 Contact: Brenda Baker Email: bbaker@northernlight.org Phone: 207-768-4151	*	663
NORTHERN LIGHT EASTERN MAINE MEDICAL CENTER 200033 Modified PC Program 489 STATE STREET, BANGOR, ME 04401 207-973-7000 Contact: Michelle Klam Email: mklam@northernlight.org Phone: 207-973-9185	*	2,657
NORTHERN LIGHT MERCY HOSPITAL 200008 PC Program 144 STATE STREET, PORTLAND, ME 04101 207-553-6868 Contact: Dawn MacFarland Email: macfarlandd@northernlight.org Phone: 207-553-6890	*	460

APPENDIX 2

HOSPITAL-BASED PALLIATIVE CARE PROGRAMS	# PALLIATIVE CARE PATIENTS SEEN IN 2021	# PALLIATIVE CARE CONSULTS IN 2021
PEN BAY MEDICAL CENTER 200063 (Maine Health) PC Program 6 GLEN COVE DRIVE, ROCKPORT, ME 04856 207-301-8000 Contact: Karin McDonald Email: Karin.McDonald@mainehealth.org Phone: 207-301-3090	*	582
RUMFORD COMMUNITY HOSPITAL 201306 (Central Maine Healthcare) **Modified PC Program** 420 FRANKLIN STREET, RUMFORD, ME 04276 207-369-1000 Contact: Amy Dugas Phone: 207-647-6159	*	*
SOUTHERN MAINE HEALTH CARE 200019 (Maine Health) PC Program 1 MEDICAL CENTER DRIVE, BIDDEFORD, ME 04005 207-283-7000 Contact: Jane Foley Email: jane.foley@mainehealth.org Phone: 207-283-7937	*	867
ST MARYS REGIONAL MEDICAL CENTER 200034 (Covenant Health) PC Program CAMPUS AVENUE - PO BOX 291 (HOSPITAL), LEWISTON, ME 04240 207-777-8100 Contact: Elizabeth Keene Email: ekeene@stmarysmaine.com Phone: 207-777-8806	*	*
WALDO COUNTY GENERAL HOSPITAL 201312 (Maine Hlth) Modified PC Program PO BOX 287, BELFAST, ME 04915 207-338-2500 Contact: Karin McDonald Email: karin.mcdonald@mainehealth.org Phone: 207-301-3090	*	*

HOSPICE-BASED PALLIATIVE CARE PROGRAMS

HOSPICE-BASED PALLIATIVE CARE PROGRAMS	# PALLIATIVE CARE PATIENTS SEEN IN 2021	# PALLIATIVE CARE CONSULTS IN 2021
ANDROSCOGGIN HOME HEALTHCARE & HOSPICE 201513 PC Program 15 STRAWBERRY AVE, LEWISTON, ME 04240 207-777-7740 Contact: Brianne (“Bree”) Genschel Email: brianne.genschel@androscoggin.org Phone: 207-740-7374	*	2,196
BEACON HOSPICE AN AMEDISYS COMPANY 201516 Modified PC Program 52 ATLANTIC PLACE SUITE B-50, SO PORTLAND, ME 04106 207-772-0929 Contact: Sandra (“Sandy”) Perrotta Email: sandra.perrotta@amedisys.com Phone: 401-719-2399	*	*
CHANS HOME HEALTH AND HOSPICE CARE 201501 (Maine Health) PC Program 60 BARIBEAU DRIVE, BRUNSWICK, ME 04011 207-729-6782 Contact: Dr. David Dumont Email: david.dumont@mainehealth.org Phone: 207-721-1201	20	*
NORTHERN LIGHT HOME CARE & HOSPICE 201502 PC Program 50 FODEN ROAD SUITE 1, SOUTH PORTLAND, ME 04106 800-757-3326 Contact: Christine (“Chris”) Turner Email: turnerc@northernlight.org Phone: 207-400-8707	*	1,637

COMMUNITY-BASED PALLIATIVE CARE PROGRAMS

COMMUNITY-BASED PALLIATIVE CARE PROGRAMS	# PALLIATIVE CARE PATIENTS SEEN IN 2021	# PALLIATIVE CARE CONSULTS IN 2021
LINCOLN MEDICAL PARTNERS PRIMARY CARE (MAINE HEALTH) AT DAMARISCOTTA Modified PC Program 24 MILES CENTER WAY, DAMARISCOTTA, ME 04543 207-563-4250 Contact: Lori Ann Email: annl@lchcare.org Phone: 207-563-4704	*	*
MARTIN'S POINT HEALTH CARE PC Program 61 BARRA ROAD, BIDDEFORD, ME 04005 207-283-1441 Contact: Dr. Teresa Letellier Email: teresa.letellier@martinspoint.org Phone: 207-286-6614	65	130

For additional information, please contact:

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CKassner@HospiceAnalytics.com
719-209-1237

2022 PREVALENCE OF PALLIATIVE CARE IN MAINE STUDY