Promoting Palliative Care Access to Persons with Cancer – A Model for Mapping Statewide Services in Massachusetts

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Background

Palliative care is part of essential services for patients with cancer. The nationally recognized definition of palliative care is : “Palliative Care refers to patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.” (National Quality Forum 2006). In order to promote access to quality palliative care as part of comprehensive oncology treatment for all cancer patients, the MA Department of Public Health surveyed various health provider agencies to understand what palliative care services existed in Massachusetts.

Results

Massachusetts Palliative Care Survey Summary Results, 2015

	SNF	Home Health/Hospice	Hospital	CHCs
Race/Ethnicity				
White	85	82.9	70.0	58.0
Black	9.0	6.4	10.0	30.0
Hispanic	6.0	10.8	12.0	22.0
Asian	1.0	6.0	6.0	4.0
Gender				
Male	43.0	42.5	47.0	39
Female	57.0	57.4	53.0	61
Health Insurance				
Medicare	34.0	76.0	60.0	42.0
Medicaid/Mass Health	48.0	14.3	17.0	9.0
Private Insurance	6.0	15.3	21.0	13.0
No Insurance	0	2.8	1.0	3.0

Quantitative Survey Results

- Availability of palliative care service in Massachusetts varied by provider
- A higher proportion of Home Health/Hospice respondents reported having a formal palliative care program compared to respondents from SNFs, Hospitals and Community Health Centers
- There were gaps in palliative care services with the majority of services concentrated in Boston and the greater Boston areas
- The Cape and Western Massachusetts reported fewer services
- The majority of respondents reported that their palliative care includes an interdisciplinary team (100% among Skilled Nursing Facilities, 84.6% among Hospitals and 84% among Home Health/Hospice agencies

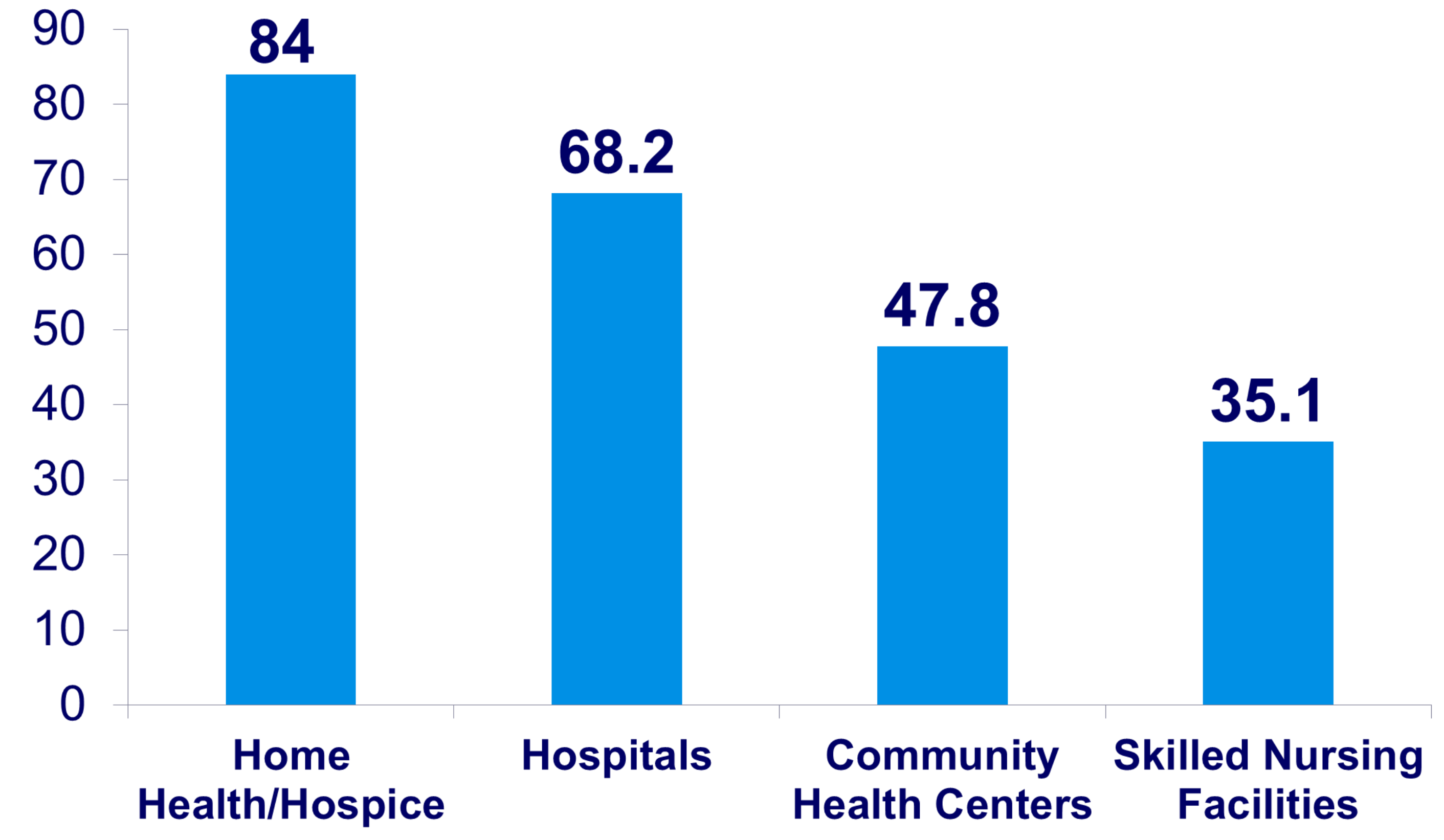
Objective

To describe the process for assessing the use and availability of palliative care services in Massachusetts using both quantitative and qualitative survey methods

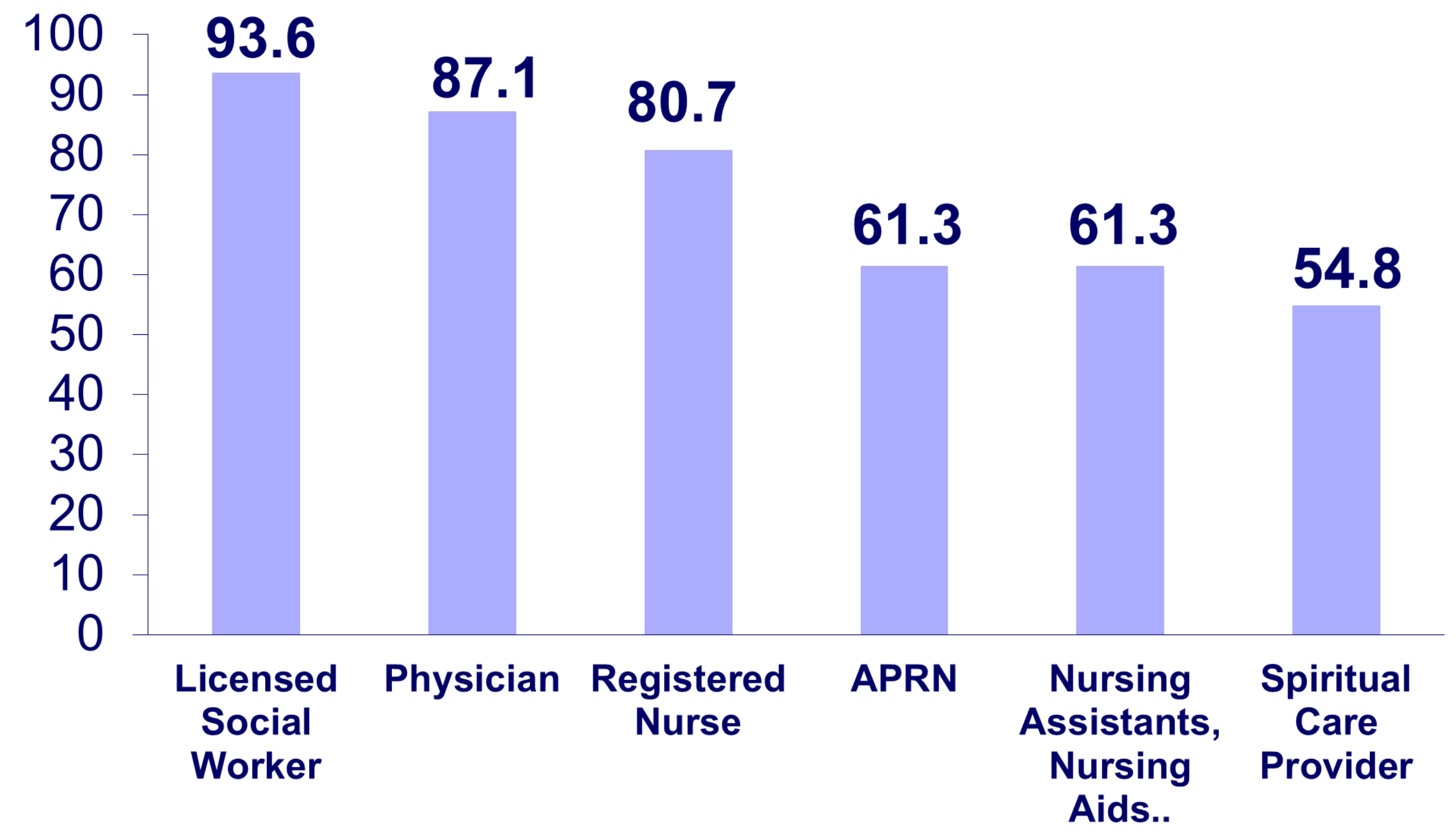
Methods

The Massachusetts Department of Public Health and the Massachusetts Comprehensive Cancer and Prevention Control Network’s Palliative Care Work Group conducted a series a statewide surveys from October 2014 to June 2015 to assess the availability and accessibility of palliative care services for all Massachusetts residents. In order to accomplish this, we surveyed palliative care service providers in Massachusetts. Phase one targeted home health and hospice organizations and phase two focused on hospitals, Skilled Nursing Facilities as well community health centers. In addition, in depth-follow-up key informant interviews were conducted to understand how and to what extent palliative care is offered and defined in organizations throughout Massachusetts. The Palliative Care Working Group provided a list of 69 possible key informants for this study. Some of key informants had previously participated in online quantitative surveys and had agreed to participate in follow-up interviews. Others represented individuals suggested by members of the Working Group to ensure that we have representation from all Massachusetts regions.

Percent of MA Palliative Care Providers with a Formal Palliative Care Program



Percent of the Leading Palliative Care Interdisciplinary Specialties among MA Home Health and Hospice Providers



Qualitative Survey Results

- Seventeen of the 24 organizations interviewed reported having a palliative care program
- Those who did not have a palliative care program were also involved in palliative as referral sources, counselors, or educators
- Palliative care is mainly done in large teaching hospitals, multi-unit organizations that provide home care and hospice services, cancer centers and oncologists, hospices, home health and some Visiting Nurse Associations
- There are confusions about the existence of palliative care among patients, families, and providers
- There also confusions regarding the meaning of palliative care
- Not clear who pays for palliative care
- Responsibility to refer a patient to palliative care is not clearly defined

Conclusions

- Although palliative care service were provided by most of the surveyed organizations, there were variations in the provision of services by organization, with most of palliative care services located in the Boston area
- Barriers to palliative care include lack of understanding of palliative care, lack of access to palliative care and the fear of “giving up” on the hope for improvement or a cure
- The general public and health care providers need to be made more aware of palliative care and understand its role in the management of chronic disease and cancer
- Health care providers need to understand the difference between hospice and palliative care and how they promote comprehensive cancer care