

# **Pancreatic Cancer in Massachusetts:**

## **Report and Recommendations from the Special Legislative Commission to Study Pancreatic Cancer**

Executive Office of Health and Human Services

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# Special Commission on Pancreatic Cancer

## Statutory Language

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### **Chapter 119, acts of 2015, Section 78. (Chap. 154, acts of 2018, Section 65)**

SECTION 78. Notwithstanding any general or special law to the contrary, there shall be a Special Legislative Commission established pursuant to section 4A of chapter 4 of the General Laws to study pancreatic cancer. The Commission shall consist of: the House and Senate Chairs of the Joint Committee on public health; the House Minority Leader or a designee; the Senate Minority Leader or a designee; 2 members to be appointed by the Senate President, 1 of whom shall be a person with pancreatic cancer or a survivor and 1 of whom shall be a medical specialist in pancreatic cancer; 2 members to be appointed by the Speaker of the House of Representatives, 1 of whom shall be a person with pancreatic cancer or a survivor and 1 of whom shall be a medical specialist in pancreatic cancer; the Secretary of Health and Human Services or a designee; the Commissioner of Public Health or a designee; the Commissioner of Insurance or a designee; and 4 members to be appointed by the Governor, 1 of whom shall be a person with pancreatic cancer or a survivor, 1 of whom shall be a medical specialist in pancreatic cancer and 2 of whom shall be members of the public with demonstrated expertise in issues relating to the work of the Commission. The Special Commission shall make an investigation and study to:

- (1) establish a mechanism in order to ascertain the prevalence of pancreatic cancer in the Commonwealth and the unmet needs of persons with pancreatic cancer and those of their families and collect time-of-diagnosis statistics and likely risks for pancreatic cancer;
- (2) study pancreatic cancer prevention, screening, education and support programs in the Commonwealth; and
- (3) provide recommendations for additional legislation, support programs and resources necessary to meet the unmet needs of persons with pancreatic cancer and their families and how to effectuate an early diagnosis and treatment for pancreatic cancer patients.

# Introduction

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An estimated 56,770 people (29,940 males and 26,830 females) will be diagnosed with pancreatic cancer in 2019; 45,750 will die from the disease,<sup>1</sup> making it the third leading cause of cancer death in the United States. According to the American Cancer Society, pancreatic cancer is estimated to be the second deadliest cancer in Massachusetts, by cancer type, with 990 deaths in 2019.<sup>2</sup> The survival rate for all stages of pancreatic cancer is 9%<sup>3</sup> and, without treatment, median survival of late-stage disease is only 3 months.<sup>4</sup> Stated another way, approximately 73% of pancreatic cancer patients die within the first year of diagnosis and 91% of patients do not survive 5 years. Early detection is difficult, as signs and symptoms most often do not appear until later stages, at which point the cancer has often spread to neighboring organs and pancreatic resection is no longer possible.

Identification of risk factors for pancreatic cancer could lead to earlier detection through awareness programs and surveillance programs for high-risk individuals.

<b>Clinical and Genetic Risk Factors for Pancreatic Cancer<sup>5</sup></b>	
<i>Clinical Risk Factors</i>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Smoking</li> <li>• Chronic pancreatitis</li> <li>• Diabetes</li> <li>• Obesity</li> <li>• Intraductal papillary mucinous neoplasm (IPMN) and pancreatic intraepithelial neoplasia (PanIN)</li> <li>• Family history of pancreatic cancer</li> </ul>
<i>Genetic Risk Factors</i>	<ul style="list-style-type: none"> <li>• p16/FAMM</li> <li>• BRCA2 and BRCA1/HBOC</li> <li>• STK11/Peutz-Jeghers</li> <li>• MSH2, MLH1/HNPCC</li> <li>• APC/FAP mutations</li> <li>• PALB2 mutation</li> <li>• PRSS1/SPINK1 mutations</li> <li>• p53/Li-Fraumeni</li> </ul>

Risk factors for pancreatic cancer include modifiable factors (those that can be changed) and non-modifiable risk factors (those that cannot be changed). Modifiable risk factors include tobacco use, being overweight, and workplace exposure to certain chemicals. Non-modifiable risk factors include age, gender, race, family history, inherited genetic syndromes, diabetes, and chronic pancreatitis.

<sup>1</sup> [https://cancerstatisticscenter.cancer.org/?\\_ga=2.171596512.1573425783.1568658262-1545852070.1568658262#/cancer-site/Pancreas](https://cancerstatisticscenter.cancer.org/?_ga=2.171596512.1573425783.1568658262-1545852070.1568658262#/cancer-site/Pancreas)

<sup>2</sup> <https://cancerstatisticscenter.cancer.org/state/Massachusetts/GqXtaGWg>

<sup>3</sup> <https://www.cancer.org/cancer/pancreatic-cancer/detection-diagnosis-staging/survival-rates.html>

<sup>4</sup> <https://jncn.org/view/journals/jncn/17/5.5/article-p603.xml>

<sup>5</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4113008/>

According to the American Cancer Society,<sup>6</sup> smoking is one of the most important risk factors for pancreatic cancer. Cigarette smoking accounts for about 25% of pancreatic cancers. The risk of getting pancreatic cancer is also higher among those who smoke cigars and use smokeless tobacco products. Pancreatic cancer risk begins to decrease once a person stops smoking. Another major risk is being very overweight or obese. Individuals with clinical obesity are 20% more likely to develop pancreatic cancer.

According to the Massachusetts Cancer Registry 2011-2015 data<sup>7</sup>, pancreatic cancer was the 9<sup>th</sup> most commonly diagnosed cancer among females and 10<sup>th</sup> among males during the study period. Incidence rates increased over that time frame, but the increases were significant only in females, rising from 10.9 cases to 12.0 cases per 100,000 females.

Pancreatic cancer incidence rates were higher among white, non-Hispanic (14.8/100,000) and black non-Hispanic (16.3/100,000) males than other racial/ethnic groups. Among females, white non-Hispanics (11.6/100,000) and black non-Hispanics (12.9/100,000) had higher pancreatic cancer incidence than other racial/ethnic groups. The median age at diagnosis was 69 years for males and 74 years for females. There were no significant differences in pancreatic cancer incidence by county.

Despite being home to several world-renowned medical institutions, Massachusetts lost 4,527 lives to pancreatic cancer between 2011 and 2015. The median age at death was 72 years and mortality was higher among white non-Hispanic and black non-Hispanic males both (12.7 per 100,000) compared to other racial/ethnic groups. Pancreatic cancer mortality rates for males remained unchanged but increased by 3% in females. Asian males had the lowest pancreatic cancer mortality (5.7 per /100,000).

In the US, 53% of pancreatic cancers are diagnosed in the distant stage (when pancreatic cancer has metastasized); 29% are diagnosed in regional stage (when the cancer has spread to nearby lymph nodes), 10% are diagnosed in the local stage (when the cancer is still confined to primary site), and 8% at an unknown stage<sup>8</sup>. Similar results were observed in Massachusetts pancreatic cancer patients.

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<sup>6</sup> American Cancer Society. Pancreatic Cancer Risk Factors. Available at:

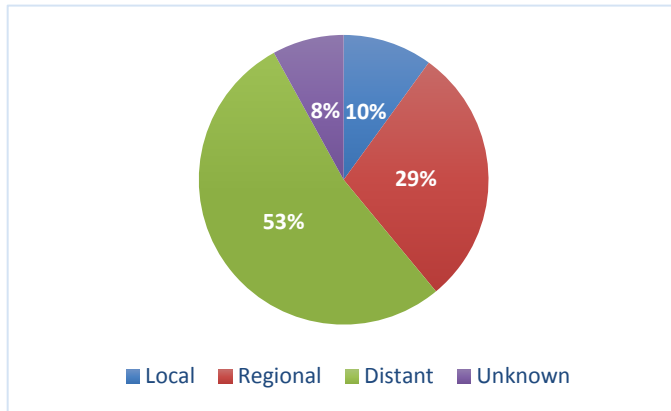
<https://www.cancer.org/cancer/pancreatic-cancer/causes-risks-prevention/risk-factors.html>

<sup>7</sup> Cancer Incidence and Mortality in Massachusetts 2011 - 2015: Statewide Report. Available at:

<https://www.mass.gov/lists/cancer-incidence-statewide-reports>

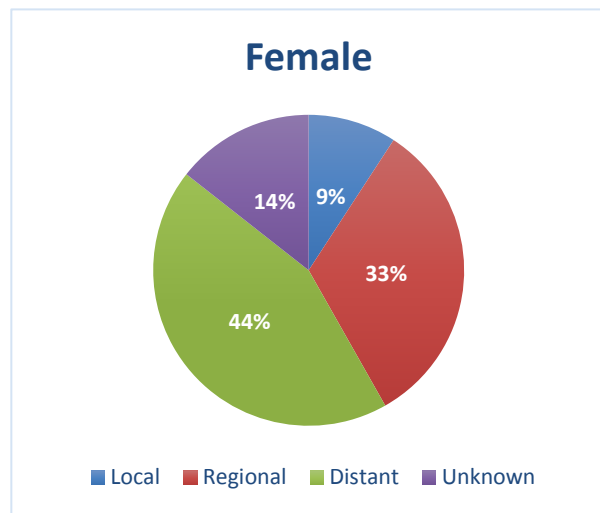
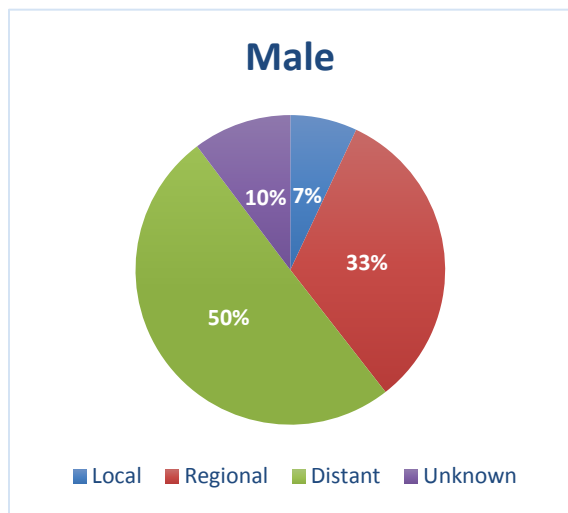
<sup>8</sup> Cancer Stat Facts: Pancreatic Cancer. Available at: <https://seer.cancer.gov/statfacts/html/pancreas.html>

**Percent of Pancreatic Cancer Cases by Stage at Diagnosis, 2013 – 2015, United States**



**Local:** Confined to primary site  
**Regional:** Spread to regional (nearby) lymph nodes  
**Distant:** Metastasized (spread further away from primary site)

**Percent of Pancreatic Cancer Cases by Stage at Diagnosis Male vs. Female, 2011 – 2015 – Mass.**



The overall survival rate for pancreatic cancer between the years of 2008-2014 was 8.5%. Survival by stage is broken down as:

- Local** – 34.3%
- Regional** – 11.5%
- Distant** – 2.7%
- Unknown** – 5.5%

# Commission Overview

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The Special Legislative Commission to Study Pancreatic Cancer has had a long history. The Commission was signed into law as part of a supplemental appropriations bill on November 2, 2015 as Section 78 of Chapter 119 of the Acts of 2015. The original amendment, unanimously passed by both the House (Amendment #18 to H.3773) and the Senate (Amendment #12 to S.2025), was introduced by State Representative Elizabeth A. Poirier of 14th Bristol District and Senator Mark C. Montigny of the Second Bristol and Plymouth District, in the 189th session of the General court. The Commission was later amended to receive staff support from the Executive Office of Health and Human Services. This amendment to the Annual Appropriations Bill for Fiscal Year 2019 was introduced by Senator Bruce Tarr of the First Essex and Middlesex District and unanimously adopted in the Senate (Amendment #412 to S.4). This second amendment was adopted by the Budget Conference Committee (House Bill 4800 of the 190th session of the General Court) and signed into law by Governor Baker on July 26, 2018 as Section 65 of chapter 154 of the Acts of 2018.

Once all the members of the Commission were identified, by either official appointment or formal designation, the first meeting was held on February 6, 2019 to formally organize. The Commission members elected Brock N. Cordeiro to serve as Chair and Cindy Callahan, RN as Vice Chair. Amy Kaplan of the Executive Office of Health and Human Services was elected Secretary. The Commission met six times (February 6, March 26, April 23, May 28, June 27 & August 27) prior to the adoption of this report on October 22, 2019.

The Special Commission to Study Pancreatic Cancer was created to identify areas of unmet needs in pancreatic cancer prevention, diagnosis, and treatment, as well as provide recommendations for additional legislation or support to meet these needs.

The 15-member Commission was charged to: (1) establish a mechanism in order to ascertain the prevalence of pancreatic cancer in the Commonwealth and the unmet needs of persons with pancreatic cancer and those of their families and collect time-of-diagnosis statistics and likely risks for pancreatic cancer; (2) study pancreatic cancer prevention, screening, education and support programs in the Commonwealth; and (3) provide recommendations for additional legislation, support programs and resources necessary to meet the unmet needs of persons with pancreatic cancer and their families and how to effectuate an early diagnosis and treatment for pancreatic cancer patients.

The Commission was comprised of the Undersecretary of Health and Human Services, the House and Senate chairs of the Joint Committee on Public Health, and a diverse panel of epidemiologists, pancreatic cancer medical specialists, as well as pancreatic cancer survivors, caregivers, and advocates. See Appendix for a list of commission members.

All of the Commission's meetings were open to the public and detailed minutes from each meeting, along with copies of all presentations and reading materials publicly considered by the Commission, were made available to the public through a webpage created for the Commission.<sup>9</sup>

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<sup>9</sup> Commission's web page: <https://www.mass.gov/orgs/the-special-commission-to-study-pancreatic-cancer>

# Commission's Charge and Recommendations

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**Charge 1: Establish a mechanism in order to ascertain the prevalence of pancreatic cancer in the commonwealth and the unmet needs of persons with pancreatic cancer and those of their families and collect time-of-diagnosis statistics and likely risks for pancreatic cancer.**

**Recommendation:** Explore a mechanism for collecting information for all pancreatic cancer patients. Collected information to include:

- Germline testing results<sup>10</sup>
- Molecular tumor analysis in patients with metastatic disease<sup>9</sup>
- Hospitals treating the highest volume of pancreatic cancer patients
- Information on stage of diagnosis
- Treatment rendered, including chemotherapy, radiation therapy, surgical treatment, neoadjuvant and adjuvant therapy
- Outcomes
- Number of patients diagnosed who did not receive any treatment or palliative care
- Number of pancreatic resections performed at each hospital and associated outcome

**Charge 2: Study pancreatic cancer prevention, screening, education and support programs for in the commonwealth.**

The incidence of pancreatic cancer itself is low, approximately 3% of total reported cancer cases. However, its mortality rate is over 90% and the median/average survival time from diagnosis to mortality is very short. While mortality rates are high, treatment options have marginally improved and chance of survival improves with earlier diagnosis.

**Recommendations:**

- Recommend a Department of Public Health (DPH)-led public awareness campaign around genetic risks, signs/symptoms, and pre-malignant conditions associated with pancreatic cancer, including new-onset diabetes, as well as the availability of clinical trials for those with pancreatic cancer.
- Partner with anti-tobacco, obesity, and diabetes prevention programs to highlight the relationships between their initiatives and pancreatic cancer, focusing on modifiable risk factors.
- Add pancreatic cancer to the list of diseases that DPH programs target with counseling for tobacco discontinuation, diet and weight management.
- Recommend that the Division of Insurance review genetic testing coverage benefits across payers, and present its findings to policy makers.
- Direct the Center for Health Information and Analysis (CHIA) to update its 2014 Mandated Benefit cost analysis for pancreatic cancer screening for high-risk individuals.

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<sup>10</sup> <https://jncn.org/view/journals/jncn/17/5.5/article-p603.xml>



***Charge 3: Provide recommendations for additional legislation, support programs and resources necessary to meet the unmet needs of persons with pancreatic cancer and their families and how to effectuate an early diagnosis and treatment for pancreatic cancer patients.***

***Recommendation:*** Enhance the multidisciplinary/specialty care (including palliative and hospice care) of all pancreatic cancer patients in the Commonwealth by creating a Pancreatic Cancer Consortium to:

- Certify/approve hospital systems that meet National Pancreatic Cancer Foundation criteria and post this information on an appropriate state website, and on advocacy websites.
- Identify institutions and/or hospital systems which could fill this role in areas that are geographically underserved and provide them with incentives to develop the necessary resources to comply in order to assure that the state is appropriately covered.
- In partnership with state government and policymakers, establish a multi-provider consortium to develop and disseminate amongst each other best practice algorithms, decision aids for Electronic Health Record (EHR) systems, and quality metrics for all phases of care in pancreatic cancer.
- Charge this statewide consortium (in partnership with other entities such as the patient organizations, National Institute of Health, American Cancer Society, etc.) to develop and maintain a portfolio of statewide clinical trials in pancreatic cancer.
- Partner with national and local advocacy groups to have all this information and links on their websites.
- Disseminate targeted communications to Primary Care Providers and their office staff to connect them with the consortium members and resources which are local to their practices.
- Utilize the local sources of the consortium members to fully operationalize existing state initiatives to identify existing cancer support services, survivorship care and counseling and expand to fit the current needs.
- Support the use of blanket consent forms (in which pancreatic cancer patients donate their tissue samples without restrictions) in all MA hospitals for tissue collection and banking for research.

## Conclusion

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Pancreatic cancer is considered to be one of the toughest cancers faced both in the Commonwealth of Massachusetts and across the United States. This is evidenced by not only the anecdotal stories of patients and their families but the data presented in this report. In light of the fact that time is rarely on the side of pancreatic cancer patients and their families, we implore the General Court to take urgent action upon our recommendations. Chief among our recommendations is the critical need to establish awareness campaigns for the early detection of pancreatic cancer to ensure more positive outcomes for patients and their families.

## Appendix

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### Special Commission to Study Pancreatic Cancer Members

Member	Affiliation
Undersecretary Lauren Peters, JD	MA Executive Office of Health and Human Services
Joshua Nyambose, PhD, MALD	Department of Public Health
Niels Puetthoff	Division of Insurance
Jody Quinn	Pancreatic Cancer Action Network
Andrew Warshaw, MD, FACS, FRCSEd (Hon)	Massachusetts General Hospital
Janice Griffin	Pancreatic Cancer Action Network
Cindy Callahan, RN	Patient Advocate
Brock N. Cordeiro	Patient Advocate
Doug Shatford	Pancreatic Cancer Caregiver
Andrea Cleghorn	Survivor
Giles Whalen, MD	UMass Memorial Health Care
Rep. John Mahoney	Massachusetts House of Representatives
Sen. Jo Comerford	Massachusetts Senate
Carole Seigel	Patient Advocate
Brian Wolpin, MD, MPH	Dana-Farber Cancer Institute

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