**Special Commission to Study Pancreatic Cancer**

Meeting Minutes

February 6, 2019

3:00-4:00 pm

Date of meeting: Wednesday, February 6, 2019

Start time: 3:02pm

End time: 4:08pm

Location: Conference Room 1, 21st Floor, One Ashburton Place, Boston, MA 02108

Members present:

* Lauren Peters – Executive Office of Health and Human Services
* Anita Christie—Department of Public Health
* Niels Puetthoff—Division of Insurance
* Jody Quinn—Pancreatic Cancer Action Network
* Dr. Andrew Warshaw—Massachusetts General Hospital
* Janice Griffin—Pancreatic Cancer Action Network
* Cynthia Callahan, RN—Patient Advocate
* Brock N. Cordeiro—Patient Advocate
* Doug Shatford—Pancreatic Cancer Caregiver
* Andrea Cleghorn—Survivor
* Dr. Giles Whalen—Umass Memorial Health Care
* Representative Kate Hogan—Massachusetts House of Representatives
* Zach Crowley—Massachusetts Senate

Members absent:

* Dr. Brian Wolpin—Dana-Farber Cancer Institute
* Carole Seigel--Patient Advocate

**Proceedings**

Undersecretary Peters called the meeting to order at 3:02 pm.

David Giannotti, Public Education and Communications Division Chief of the State Ethics Commission, provided the commission with a brief overview of the State’s conflict of interest and ethics regulations. He explained commission members’ status as special state employees, and explained the considerations related to conflicts of interest and mandatory online ethics training they are required to complete within 30 days of their appointment.

Lauren Cleary, Associate General Counsel for the Executive Office of Health and Human Services, provided an overview of the Open Meeting Law. She emphasized the importance of transparency and reminded commission members that records, documents, and minutes from the commission’s meetings are public records.

Undersecretary Peters opened the discussion. Members briefly introduced themselves, noting relevant affiliations. Afterwards, Undersecretary Peters gave a brief introduction and summary of the commission’s charge.

Undersecretary Peters explained that EOHHS has been charged with staffing the commission, and that this commission shall appoint its Chair, Vice Chair, and Secretary.

**Vote:**  Undersecretary Peters introduced a motion for Mr. Cordeiro to serve as Chair, which was seconded and unanimously approved.

**Vote:**  The chair introduced a motion for Ms. Callahan to serve as Vice Chair, which was seconded and unanimously approved.

**Vote:**  Dr. Warshaw introduced a motion for Amy Kaplan, EOHHS, to serve as Secretary, which was seconded and unanimously approved.

Undersecretary Peters moved to the next item of the agenda, to discuss the logistics and timing of the commission’s work. The commission discussed and the Chair decided that the commission will aim to meet roughly monthly and submit a report to the legislature by the end of 2019.

The commission discussed their individual scheduling restrictions, and potential locations for future meetings.

Undersecretary Peters asked if there were other relevant issues not explicitly stated in the charge that the commission would like to examine. Dr. Warshaw expressed confusion about the roles of individual members in achieving each charge, and Undersecretary Peters explained that it is the group’s responsibility to determine what data sources would be best to go to for certain pieces of information or reporting, and that EOHHS would help facilitate communication with those sources. Ms. Christie offered that DPH’s cancer registry can be of use to the commission’s work in providing staging and prevalence information.

Undersecretary Peters summarized that the commission shall “align to say, ‘this is how we define what we’re looking for,’” and then identify the best way to pull that data. She clarified that the commission shall share the work of compiling data and drafting the final report. She clarified that the commission could consider the end goal of its work, to present clear information to the legislature to help guide their thinking, and that members should think about what information is most useful to that end. She mentioned specific considerations, such as the best way to present data, how to track data over time, how to include data trends, how to present the “regionality” of data across the commonwealth, and which “cuts” of data to include.

Ms. Cleghorn asked whether the commission will break into subcommittees.

The Chair explained that while having “subcommittees for the sake of subcommittees” is not the goal, if the commission feels that they would be useful to tackle objectives more deeply, then subcommittees may be used.

Undersecretary Peters emphasized that every member brings a different background and expertise to this work, so certain members may be leaned on for input more heavily when discussing certain areas than others.

Dr. Warshaw expressed that the trend of Pancreatic Cancer prevalence is increasing nationally, and that it may be important to look at changing methods of evaluation and treatment. He went on to say that the field is changing rapidly both in terms of available treatment and outcomes. He emphasized that the location of treatment, whether in rural community health centers or centralized large medical centers can produce widely disparate outcomes. Ms. Quinn agreed with this assessment, emphasizing that primary care providers in rural community health centers may not have completely up to date information about treatment options.

Undersecretary Peters suggested that the next meeting’s agenda could focus on defining the data that the commission would like to ask DPH to produce for examination.

The Chair agreed, and asked whether or not remote participation would be an option for future meetings.

Undersecretary Peters explained that this could be voted on, but that meetings during which remote participation took place would need to adhere to the Open Meeting Law rules, including a requirement for a physically present quorum of members.

**Vote:** The Chair introduced a motion to allow for remote participation, which was seconded by Dr. Whalen, and unanimously approved.

Dr. Warshaw asked if Mr. Puetthoff was representing the Division of Insurance on this commission in order to provide perspective on treatment cost. Mr. Puetthoff explained that his perspective would be around the types of coverage patients have, and within the types of coverage, what kinds of policies are in place, and what degree of cost-sharing is involved. He offered that these issues may be something to consider when assessing unmet need, whether or not levels of coverage or cost-sharing is a deterrent to care. Ms. Griffin agreed, stating that while some patients have proper and adequate insurance, but others do not, which affects their quality of care. Dr. Warshaw agreed that this constitutes “a whole category of barriers to care.”

Undersecretary Peters mentioned that this discussion falls under the “first prong” of the commission’s charge, and can be discussed further at the next meeting.

**Vote:** The chair introduced a motion for the meeting to adjourn, which was seconded and unanimously approved.

The meeting was adjourned at 4:08 pm.