



Parkinson's Disease Registry Advisory Committee Meeting Minutes

Date: Wednesday, January 26, 2022 (1:30 – 3:30 pm)
Location: Zoom (<https://umass-amherst.zoom.us/j/98888409321>)
Materials Provided: Meeting agenda.

Committee Members:

Lauren Fogarty, Dr. Samuel Frank, Dr. Anindita Deb, Dr. Terrell Johnson, Dr. Glenn Tucker, Brett Miller, Cathi Thomas, James Cornell, Matt Keswick

Others Present:

Mary Lou Woodford, Casey Hall, Jim Ballin

Call to Order by Project Manager Mary Lou Woodford

Roll Call:

- Cornell, present
- Deb, present
- Fogarty, present
- Frank, present
- Johnson, present
- Keswick, present
- Miller, present
- Thomas, present
- Tucker, present

I. Welcome & Introductions

II. Overview of Committee's Charge and Deliverables

Presented by Mary Lou Woodford, project manager.

SECTION 45. Chapter 111 is hereby further amended by adding the following Section 243.

- (a) The department shall establish a Parkinson's disease registry for the collection of information necessary to determine the incidence and prevalence of Parkinson's disease in the commonwealth
- (b) There shall be within the department, a Parkinson's disease registry advisory committee to advise and assist in the development, implementation and progress of the Parkinson's disease registry established in subsection (a).



The committee shall review and submit recommendations on:

- (i) what data shall be collected, including, but not limited to, demographic information and data by areas and regions of the commonwealth, with specific data from urban, low and median income communities and minority communities of the commonwealth
- (ii) the means of collecting and disseminating such data
- (iii) how to ensure privacy and confidentiality of such data
- (iv) the purpose, design and functionality of the registry
- (v) the implementation of the registry

The committee shall recommend to the department any information deemed necessary and appropriate for the statistical identification and planning for treatment and education of health care providers and persons diagnosed with Parkinson's disease.

"The committee shall consist of the commissioner, or a designee, and 10 members to be appointed by the commissioner as follows: 3 physicians, 1 of whom shall be a general neurologist, 1 of whom shall be a movement disorder specialist and 1 of whom shall be a primary care physician; 1 health informaticist; 2 population health researchers familiar with registries; 2 Parkinson's disease researchers; and 2 persons diagnosed with Parkinson's disease. The committee shall meet at least bi-annually to assess registry progress and recommend changes."

Woodford: Two vacancies on the board with two Population Health Researchers needed for remaining seats.

III. Open Meeting Law and Conflict of Interest Policy

Presented by Jim Ballin, counsel at the Massachusetts Department of Public Health.

- The purpose of OML is transparency in government.
- All meetings of a public body must be open to the public.
- A public body includes any multi-member board, commission, committee, or subcommittee if established to serve a public purpose.

Deliberation:

- A meeting is "a deliberation by a public body with respect to any matter within the body's jurisdiction."
- Deliberation is defined as "an oral or written communication through any medium, including electronic mail, between or among a quorum of a public body on any public business within its jurisdiction."
- Deliberation does not include scheduling or procedural information.
- If a quorum of a public body wants to discuss public business within that body's jurisdiction, they must do so during a properly posted meeting.
- NOTE: If a public body member sends an email to a quorum of the public body expressing an opinion on any matter that could come before that body, the communication violates the OML, even if no recipient responds.



Posting Notice of Meetings:

- A public body must post notice of its meetings on its website at least 48 hours before the meeting, excluding Saturdays, Sundays, and legal holidays.
- The notice must include the following:
 - Date;
 - Time and place; and
 - List of topics the chair reasonably anticipates will be discussed at the meeting.
- The list of topics should provide sufficient information to inform the public of the issues to be discussed at the meeting.

What is a Quorum?

- A Quorum is defined as:
- A simple majority of the members of a public body, unless otherwise provided in a general or special law, executive order, or other authorizing provision. G.L. c. 30A, § 18.
- As applied to the Advisory Committee for Parkinson's Disease Registry, the quorum equals 6 members ($\frac{1}{2}$ of 11 members + 1)

Avoiding OML Violation – Best Practices Recommendations:

- Public body members must not engage in “serial deliberations”—a series of separate, independent conversations outside of a meeting among a quorum of the members regarding a topic within its jurisdiction.
- In order to avoid even the appearance of a potential OML violation, the AGO advises public body members to refrain from communications over email except for distributing meeting agenda, scheduling meetings and distributing documents created by nonmembers.

Remote Participation:

- Chapter 20 of the Acts of 2021, An Act Extending Certain COVID-19 Measures Adopted During the State of Emergency (June 16, 2021), authorizes remote participation of public bodies through April 1, 2022:
- Public bodies are permitted to have live “adequate, alternative means” of public access, including video conference;
- Remote participation is allowed by all members of the public body; and
- All votes taken during a meeting in which a member participates remotely must be by roll call vote.

Public Meetings – Miscellaneous

- A member of the public may not address the public body without permission of the chair.
- A member of the public may not disrupt the meeting.
- The public body must create and maintain minutes of all meetings.
- Records reviewed by the public body during the meeting are public records.
- The Attorney General's Office enforces OML.
- A member of the public may file a complaint alleging an OML violation, first with the public body, and subsequently with the Attorney General's Office if necessary.

Conflict of Interest Law



- The Conflict of Interest (COI) law, M.G.L. c. 268A, is meant to prevent conflicts (and appearances of conflict) between a state employee's private interests and his or her public duties.
- As statutory public body members, you are considered to be "special state employees" subject to the COI law.
- The COI law is complex; State Ethics Commission attorneys are available, through the "Attorney of the Day" program, to provide confidential advice/guidance on how the COI law applies to you in a particular situation.
- Contact Attorney of the Day @ (617) 371-9500
- All state employees subject to the COI law are required to:
- Certify they received and reviewed the annual Summary of Conflict of Interest Law, and
- Complete the biannual online training program

IV. Member Discussion of Committee Expectations

No comment.

V. Election of Chair(s)

Member Cornell submits nomination of Cathy Thomas and Brett Miller as co-chairs, seconded by Tucker.

Thomas and Miller accept.

Roll call: Affirmed by unanimous vote of all members.

VI. Next Steps

Member Frank indicates concern with the next proposed meeting date occurring during school vacation.

Wednesday, February 16th from 2pm to 4pm adopted as next meeting date, further setting of meeting dates deferred to subsequent meetings.

Discussion of various considerations for future meetings, including data collection procedures, other registries and committees which might serve as models or guidance, scope of neurodegenerative and movement disorders to include under this committee, scope of data collected, envisioned purpose for data collection, need for further legislative action to authorize data collection.

Action steps before next meeting:

- Thomas: Requests that Dr. Frank presents on diagnoses, request that members do a review of available literature and data on existing registries.
- Fogarty: Will look into ALS registry.
- Keswick: What are the identified fields for collection in other registries and states? Suggests one-pagers on each.



- Tucker: Will gather best-practices and recommendations on registrations; consider relevant data collection avenues.
- Woodford: We can invite presenters to speak as desired.
- Frank: Accepts member Thomas's request for presentation.

Motion to adjourn from Mary Lou, seconded by Tucker.

- Roll call:
 - Affirmed: Fogarty, Frank, Johnson, Tucker, Miller, Thomas, Keswick.
 - Not present: Deb, Cornell.