



Parkinson's Disease Registry Advisory Committee Meeting Minutes

Date: Wednesday, May 11th, 2022 (2:00 – 4:00 pm EST)

Location: Zoom (<https://umass-amherst.zoom.us/j/93968180415>)

Materials Provided: Meeting agenda, presentation slide deck

Committee Members:

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

Others Present:

Mary Lou Woodford, Casey Hall

Call to Order by co-chair Cathi Thomas, seconded by Lauren Fogarty

Roll Call:

- Cornell, not present
- Deb, present
- Fogarty, present
- Frank, not present (arrived late)
- Johnson, present
- Keswick, present
- Miller, not present (arrived late)
- Thomas, present
- Tucker, not present (arrived late)

I. Welcome

Motion to accept minutes from the 4/13/22 meeting by co-chair Thomas, seconded by member Fogarty.

Members present unanimously accepted proposed minutes.

II. Review of Draft Report

Draft report presented by coordinator Mary Lou Woodford with comments from committee members.

Introduction

Background

Member Terrell suggests acknowledgement of lack of existing data, nationally and in Massachusetts.



Executive Summary

Mary Lou comments on underrepresented components.

Fogarty: Include language about application process for research requests.

Thomas: Still need to draft a proposed budget.

Keswick: Raising the need for both start-up and ongoing budgets.

Mary Lou: Appendix A to include proposed budget justification, can include further detail.

Tucker: We should recommend budget research in the report.

Keswick: Uncomfortable with staffing language stating 4.0 FTE. Prefer to recommend skillsets than dictate staffing.

Mary Lou to generate a comparison table of existing registries and their costs for the committee to review as a possible alternative to stating explicit funding requirements.

Purpose, Design and Functionality

Frank: Request acknowledgement of lack of information regarding reporting data transmission and generation, request for clear language in this section regarding the committee having researched multiple registries in multiple states.

Mary Lou: Proposed implementation guideline generation can account for reporting specifics.

Privacy and Confidentiality

Frank: Include recommendation to support public outreach and education for the PD community to address concerns.

Mary Lou: May also include recommendations for clinical outreach and education.

Implementation

Frank: Be sure to include existing federal programs as opportunities.

Recommendations

Frank: Phase 3 may be overly large. Splitting out data process may be more manageable.

Deb: Concern about pilot placement in the progression.

Fogarty: Request more specificity regarding pilot.

Frank: Recommend amendments being limited to Phase 4.

Tucker: Include language about anticipated ongoing evolution of the registry to account for changes in the field.



Appendix A–D

PD Resources in MA

Thomas: to gather resources and is looking for input.

Acknowledgements

Additional discussion of public outreach and raising awareness.

Keswick: Request to align committee member list with list of qualifications dictated for the committee. Request to acknowledge ongoing role of the committee beyond issuing the report.

Committee reviewed availability of members for May 25th meeting before setting 2 pm start time.

Motion to adjourn by Tucker, seconded by Keswick.

Meeting closed with unanimous vote.