MARYLAND PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE
MINUTES
AUGUST 22, 2022
1:00 - 4:00 PM

The Maryland Parkinson's Disease Registry Advisory Committee held a public meeting on 8/22/2022, called to order at 1:04 P.M.

MEMBERS PRESENT
Asima Cheema
Ian Edwards
Josh Gottesman
Fei Han
F. Rainer von Coelln
Larry Zarzecki

MEMBERS NOT PRESENT
Dawn Lewis
Xiaobo Mao
Sohail Qarni

MDH STAFF PRESENT
Kristi Pier, CCDPC
Jessica Rose-Malm, CCDPC
Kimberly Stern, Cancer Registry

MEMBERS OF THE PUBLIC PRESENT
Laura Mandel, CRISP
Bill Pitcher, HB Strategies
Sarah Peters, HB Strategies
Julia Worcester, Michael J. Fox Foundation

I. **Welcome, Roll Call, and Review of Agenda and Objectives**
    Kristi Pier, Director of the Center for Chronic Disease Prevention and Control (CCDPC) at the Maryland Department of Health (MDH), called the meeting to order at 1:04pm. Ms. Pier took roll call, reviewed the meeting agenda, and objectives. The objectives of this meeting were to 1) make a decision about the utility and feasibility of a Maryland Parkinson's disease registry, and 2) outline recommendations for the legislative report. The meeting was originally planned as in-person, however due to last minute changes in member availability, MDH opted to hold a fully virtual meeting.

II. **Discussion: Use of a Parkinson's Registry**
    Ms. Pier presented findings from a survey of Parkinson's Disease Registry Advisory Committee members in which members described how they would use data from a Parkinson's disease registry. Responses fell into three categories: 1) clinical uses to identify risk factors and assess treatment effectiveness; 2) research uses to identify gaps in knowledge; and 3) service or systems uses to identify and address disparities in care. In response to the survey findings, members pointed out the absence of direct benefit to people with Parkinson's disease. Members agreed that registry data could reveal disparities and inequities and inform deployment of resources to address them. Members reiterated the importance of starting small and relatively superficial with data collection, laying the groundwork for expansion to more complex data and/or other neurological disorders.

III. **CRISP Parkinson's Disease Data**
Laura Mandel, Public Health Data Lead at CRISP, presented on the function and reach of the Chesapeake Regional Information System for our Patients (CRISP), Maryland's state designated health information exchange. CRISP holds de-duplicated patient-level data for patient encounters at hospitals and on-site ambulatory care facilities since 2013. CRISP captures very little data from smaller ambulatory practices. CRISP records contain ICD-10 diagnostic codes, including those for Parkinson's disease, however additional clinical data is inconsistently reported. If legislation mandates provider reporting of patient-level data, CRISP can be designated to collect the data on behalf of MDH. The Committee also discussed including data release from the Vital Statistics Administration in any proposed Parkinson's disease registry legislation, as pairing case data with death records is critical for accurately determining prevalence.

IV. **Guided Conversation: Registry Purpose**
Ms. Pier led the Committee in a conversation about the registry's purpose. In the pre-meeting survey, members agreed the primary purpose would be to collect and store meaningful data about Parkinson's disease. Members suggested using the data for several purposes, such as advancing research, understanding variations in prevalence, improving treatment and care for people living with Parkinson's disease, and informing funding decisions to support improved access to care, education, coordinated services, and other resources. During the guided conversation, members pointed to the role of a registry as a tool to reveal need and inform decision-making. To be an effective tool, the data collected must be actionable. Members also felt it was important for the registry to be built in a way that is adaptable and capable of growing, changing, and expanding over time as knowledge and needs change. Finally, members felt it was important to include the impact for patients and caregivers in the registry's purpose.

Following the guided conversation, Ms. Pier held an informal poll and members unanimously agreed the identified purpose justifies building a registry in Maryland. This was not a formal Committee vote.

V. **Defining a Registry: Parameters**
Ms. Pier asked Committee members to conclude their discussion of the registry's purpose by developing a consensus purpose statement. Due to time constraints, members were instructed to review the purpose statements from other state registries and post their suggestions in the Basecamp message board prior to the next Committee meeting.

VI. **Data in the Registry**
Jessica Rose-Malm of the CCDPC led a discussion of necessary data elements to include in a registry to achieve the purpose described in earlier conversations. The Committee discussed the need to gather meaningful, actionable data while minimizing the reporting burden for providers. Committee members used a virtual whiteboard to review and prioritize data elements suggested in the pre-meeting survey. The highest priority data elements included: 1) patient identifiers and demographics (name, date of birth, address, sex, race, ethnicity; 2) diagnosis (Parkinson's disease or Parkinsonism); and 3) age of onset or diagnis date. Members discussed whether

VII. **Discussion of Next Steps**
Ms. Rose-Malm reviewed findings from the pre-meeting survey in which Committee members

brainstormed the infrastructure, staffing, regulation, and resources needed to develop, implement, and maintain a registry. Members recommended looking to models from other states, specifically California, for guidance on how to design the registry infrastructure. Staffing suggestions included IT staff, epidemiology and data analysis staff, and program staff to support overall management, communications, and outreach and education. Members agreed mandatory reporting of Parkinson's cases would be necessary to populate the registry and advised working with MDH or other entities to develop reporting regulations and guidance.

VIII.   **Public Comment**

Ms. Pier invited members of the public to share questions or comments with the Committee. No members of the public made comments.

IX.   **Closing**

Ms. Pier thanked Committee members and members of the public for their participation. Ms. Pier closed the meeting at 3:51 pm.

Next Committee Meeting: September 7, 2022