



**HEALTH/CARE OUTCOMES AND DISPARITIES WORKING GROUP of the
PARKINSON STUDY GROUP**

Introduction

We care for those affected by Parkinson disease in a time when academic physicians in all specialties are appropriately placing increased focus on patient, clinical and system outcomes. Leaders in academic medicine have also begun to accept the responsibility of ensuring equitable access to state of the science care and research opportunity, given the mounting evidence that disease risk and treatment response may differ substantially across patient subgroups. The Health/Care Outcomes and Disparities Working Group of the Parkinson Study Group (PSG) aims to advance clinical research and understanding of the patient, provider, and system level contributors to clinical, societal, and economic outcomes in those affected by Parkinson Disease, producing data that will support quality goals and policy recommendations aimed at improving the care and well-being of those with PD.

Goals of the Outcomes/Disparities Working Group

The Outcomes and Disparities Working Group will have the following goals and specific activities described below:

- 1) To increase awareness of health/care outcomes and disparities in PD within PSG, among clinicians, researchers, and funding agencies.
- 2) Incorporate Outcomes and Health Services Research into PSG research activities. This will include evaluating current PSG data, sites, other PSG working groups and PSG membership expertise to identify gaps in knowledge, collaborative potential and high impact research opportunities.
- 3) Perform original and multidimensional health outcomes research (patient centered, patient reported, functional status); perform original research designed to produce actionable observational data on disparities in health, health care and outcomes in PD, working with other PSG members and transdisciplinary experts to identify and characterize modifiable clinical, physiological, treatment and utilization factors that are associated with the observed disparities.
- 4) Improve the delivery of PD care to vulnerable populations and use the network of PSG sites to test and implement measures to improve outcomes and reduce disparities in health and care in PD.
- 5) Foster the development of new investigators across multiple disciplines with expertise in health services, disparities and outcomes in PD and incorporate outcomes and disparities research into the annual PSG conference.
- 6) To counsel appropriate PSG bodies (e.g., Executive Committee, Scientific Review Committee, Mentoring Committee, steering committees of clinical trials) to provide assessment of 1) health disparities (differential access, utilization, comorbid disease burden, and health behaviors), 2) health services (utilization, economic) and 3) outcomes (clinical, survival, avoidable outcomes, and comparative safety) for PSG studies. We will develop strategies for collection of utilization and outcomes data in future PSG studies and methods to adjust for recruitment bias.
- 7) Disseminate information about PSG Health/Care Outcomes and Disparities Working Group activities, research findings via presentations at meetings, publications, patient organizations and community support groups.

Potential Scope of WG Activity on Health/Care Outcomes and Disparities

Examples of topics addressed by ODWG: patient differences in clinical phenotype/progression, survival, functional status, quality of life, patient centered outcomes, patient-provider relationship, care models, health care utilization,

short/intermediate/long term clinical outcomes, avoidable clinical outcomes in PD, cost effectiveness, cost-utility, intangible costs and benefits.

Examples of preliminary ideas for projects proposed by WG leadership:

- Testing and refinement of Quality Initiatives for management of PD (PDQI) proposed by the AAN.
- Feasibility of internet based CME modules for improved Primary Physician treatment of PD in areas with poor neurologist access.
- Prospective cohort study of underrepresented PD patients (most elderly, rural, women, non-whites)
- Frequency of infectious disease screening in PD and association with clinical outcomes and avoidance of systemic infection
- Development of guidelines for infectious disease screening and treatment of bacteruria in PD and PD with dementia
- Exploration of patient level contributors to utilization of specialist care, adaptation of recommended treatment(s)
- Cost of informal care provided by family members in suboptimal treatment of PD.
- Productivity and Quality Adjusted Life years gained from

Procedures for Member Initiated Proposals

The procedures for application for PSG studies and for conduct of the approved studies are explained in the PSG Constitution & Bylaws, Article X. All PSG proposals have to be reviewed by the Scientific Review Committee, and then a decision will be made by the Executive Committee, based on the recommendation of the Scientific Review Committee. However, before this formal stage is reached, the ODWG can act as a facilitator for the discussion and development of the project as a “pre-proposal”. Similar to other working groups in the PSG, the ODWG leadership will periodically announce request for pre-proposals that can be submitted using a special form and be discussed with the interested WG members by e-mail, conference calls, and eventually during WG meeting during the annual PSG meeting. Article XII of the PSG Constitution & Bylaws explains the Publication Policies that result from PSG projects.

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