I. Background

In recent years, value-assessment (VA) bodies have instituted new opportunities for patients and other stakeholders to engage in treatment reviews. These expanded engagement opportunities have revealed significant deficiencies in traditionally collected data. Data on outcomes or other patient/caregiver impacts (e.g., patient and caregiver employment or presenteeism, financial toxicity) are useful for determining value of new medical products from the patient perspective. However, these aspects of patient and family experience data are rarely systematically collected. As a result, patient groups in partnership with value-assessment bodies have conducted disease-specific patient and family surveys to fill data gaps. For example, the Multiple Sclerosis Coalition and the Institute for Clinical and Economic Review (ICER) fielded a survey to collect data on disease and treatment impacts including employment, insurance coverage, finances, and quality of life.1 Similar surveys have been fielded by other patient groups, including for peanut allergy and sickle cell disease.2,3

If patient groups more routinely gather impact data needed to inform a value assessment, they will be more equipped to efficiently accommodate requests from and engage with value-assessment bodies. Many patient groups already have registries and/or conduct surveys, and use other input and data-collection methods. However, they may not be collecting data needed for value assessment and data quality may not be sufficient for these purposes. Earlier and more routine data collection could improve efficiency and existing data-collection efforts could be improved for. For example, it may be possible for patient groups to incorporate additional questions into existing registries and collect data over time rather than in one-off, cross-sectional efforts only in conjunction with a value-assessment body’s request. But, patient groups are unsure about what to collect or if the assessment bodies will even use the data. Value-assessment bodies have worked with groups one-on-one, but have not put out data preferences or standards on what is desired.

To move beyond ad hoc engagements and improve efficiency and data quality, a standardized template of survey questions would help to inform data collection for patient-centered value assessment. A patient-group led, multi-stakeholder effort is needed to develop this standard template questionnaire and supporting tools for patient groups to conduct the data collection.
Objective

The objective of this request for applications is to identify a pre-doctoral fellow and fellow mentor (who will be the principal investigator) with interests in patient-centered outcomes research and value assessment to conduct a multi-stakeholder research project to:

- Develop and pilot test a template set of standard survey questions for patient groups to incorporate into existing registries or field as a stand-alone questionnaire to prospectively and routinely collect patient-provided information informative to and used by value-assessment bodies;
- Develop training materials to help facilitate uptake of the survey template;
- Disseminate the template to key audiences, including patient organizations, value assessment bodies, and health economists.

The National Health Council

Created by and for patient organizations 100 years ago, the National Health Council (NHC) brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, sustainable health care. Made up of more than 140 national health-related organizations and businesses, the NHC’s core membership includes the nation’s leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

II. Fellowship Description

Duration: 18 months

Overview:

The pre-doctoral fellow, under the supervision of a mentor, will lead a project to rigorously and systematically develop a methodologically sound survey template that can be used by patient organizations or others to collect patient-experience and other data from a patient community (through registries, surveys, and other means) for the purpose of filling data gaps encountered when conducting value assessment. Tools and educational materials will also be products of the program.

There is an expectation the work will lead to:

- First-authored peer-reviewed publication(s).
• Opportunities to collaborate on other smaller, but related projects at the NHC in overlapping areas of interest
• Opportunities to collaborate with other researchers
• Engagement with relevant patient groups, government agencies, academic institutions, and industry representatives
• Potential guest lecture opportunities
• Mentoring by NHC and its members’ staffs
• Attendance/presentation at a relevant, national conference

Candidate characteristics:

• A current PhD candidate in an accredited doctoral program, with an expectation of program completion before December 31, 2022.
• Research skills and career aspiration in areas related to mixed-methods research, psychometric research analyses, survey design, and related methods, analytics, and approaches.
• U.S. Citizens or permanent residents.

Location: The Fellow will be based at their home institution and will attend meetings virtually or at the NHC in its Washington, D.C. office as needed. Please note at present, the NHC office is closed due to the COVID-19 pandemic.

Application Instructions:

Applications due: April 28, 2021 by 5 pm ET
Please submit your application to: nhcprograms@nhcouncil.org
Application Components:

1. Cover letter prepared by the pre-doctoral fellow candidate, which should include the applicant’s:
   • Statement of interest in and experience with the topics of patient-centered outcomes research and value assessment,
   • Description of related research, methods, and analytic experience and capabilities, and
   • Future career aspirations and plans in the field of patient-centered outcomes research and value assessment.

2. Letter of support from the mentor who will serve as the principal investigator, which should include:
   • Statement of support for the project and dedication of time to mentor the Fellow,
   • Description of related personal experience and qualifications, and
   • Description of fellow applicant’s related experience and qualifications.

3. Principal investigator (mentor) CV

4. Predoctoral fellow applicant CV
5. Funding:
- This award is limited to $50,000 for student stipend support and fees associated with doctoral training for up to 18-months.
- Awardees must provide the National Health Council with a satisfactory progress report upon completion of the first ten months of funding. In addition, applicants must provide a letter from their thesis adviser, confirming that satisfactory progress is being made.
- The program provides no other subsidies (i.e. travel, fringe benefits, etc.)
- National Health Council funds may not be used for fringe benefits or indirect costs to the university.
- Payments will be made directly to the university on a quarterly basis.
- Awards may be activated beginning May 15, 2021 or on the first day of any month thereafter, up to and including December 1, 2021.
- A financial report will be required upon completion of the first twelve months of funding.
- A final progress report and financial report will be required at the conclusion of the fellowship.
- Unspent funds are to be returned to the National Health Council.
- These funds are non-transferable.
- Any changes to the proposed project must be approved by the National Health Council.

The following items should not be included in the budget, but will be covered by the Fellowship sponsor for program completion:
- Compensation to patient-group representatives involved in the program
- Travel to one meeting to present findings
- Open access fee for one manuscript publication