



Measuring Experiences in Shared Health decision making in Real clinical care (MESHR)

Lead Researcher(s):

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Lead Alliance representative(s)

To be determined

Background and Study Description

There is often more than one reasonable path forward in most medical decisions, including possibly the option of doing nothing, where appropriate. This is especially true in the context of chronic health conditions such as cardiovascular disease. Each path might be associated with a combination of intended effects and side effects. The process whereby the patient and a healthcare provider find the optimal option for the patient is referred to as Shared Decision Making (SDM), and is a central concept in patient centered care. There is growing evidence for improvement in outcomes when SDM occurs however, there is currently no easily implementable measure for assessing SDM practices in the clinical care setting.

We propose to develop an easily implementable measure that would be relevant to decision making in any clinical context that enables the assessment of the extent and effectiveness of SDM. To achieve this objective we will build on the existing evidence base by leveraging the diverse patients and other stakeholder perspectives available through the PCORnet patient-powered research networks (PPRNs) to identify the most important, common SDM indicators and outcomes across different health conditions, clinical settings and patient characteristics. We will use these criteria to develop an appropriate matched measure targeting the healthcare provider – patient dyad. These measures will then be pilot-tested in different clinical setting in several different health systems through the infrastructure provided by the PCORnet clinical data research networks (CDRNs).

We are looking to partner with PPRNs such as Health eHeart to suggest a member for our stakeholder group (associated with an honorarium) to contribute throughout the project period. Additionally, to send/post information about the study to your registry to help recruit participants for the qualitative interviews portion of the study. The stakeholder group participant will also help/advise on the content and language of the developed measure.

How this study meets Health eHeart Alliance criteria for sponsorship

1. Cardiovascular-related research.

Chronic health conditions such as cardiovascular disease often have many possible treatment options and SDM is a central concept in patient-centered care for these individuals.

2. At least one Health eHeart Alliance member is participating as a patient-leader in a decision-making role and getting compensated for that role.

We would look to Health eHeart to suggest one member for our stakeholder group to assist with developing the qualitative study protocol as well as the content and language of the subsequently-developed SDM measure for pilot testing. This role would be associated with a yearly honorarium.

3. Accountability reporting on study progress and results back to the Health eHeart Alliance Community and the Steering Committee.

The study investigators will report back to the Health eHeart Alliance Community and Steering Committee regarding the status of the funding application. If funded, study progress and results would be communicated back via the Health eHeart patient representative on the study's stakeholder group.

4. Co-authorship for at least one Alliance patient-leader on final results paper.

Members of our stakeholder group, including the Health eHeart designated representative, will be offered the opportunity to be involved in manuscript development. Based on meeting journal-specific manuscript contribution requirements, the Health eHeart patient representative will be a co-author on the final results paper.

5. Acknowledgement of the Health eHeart Alliance in the final results paper.

The Health eHeart Alliance will be acknowledged in all publications and presentations.

6. Adequate funding.

We are currently applying for funding from the Agency for Healthcare Research and Quality in response to the call for proposals, PA-16-424, and are requesting adequate funding to cover the honoraria for the Health eHeart representative for the project period April 1, 2018 – March 31, 2021.