UM-KECC Technical Expert Panel
Patient Reported Outcomes (PRO) Recommendations

Project Overview:
The Centers for Medicare and Medicaid Services (CMS) tasked the University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) to develop a white paper on Patient-Reported Outcomes (PRO) that explored existing End-Stage Renal Disease (ESRD) patient-reported outcome measures as well as other PRO measure areas of interest to ESRD patients and other stakeholders in the renal community. The white paper submitted to CMS outlined several recommendations including potential measure development. The final paper was publically posted on January 6, 2017 and is now publically available here-
https://www.dialysisdata.org/sites/default/files/content/ESRD_Measures/Patient_Reported_Outcomes_Report.pdf. As a next step, UM-KECC is convening a TEP to review a set of existing PRO measures and to make recommendations for development. This work is performed under the ESRD Quality Measure Development, Maintenance, and Support contract (HHSN-500-2013-13017I).

TEP is a group of subject matter experts and stakeholders who provide input on the development and maintenance of measures for which the contractor is responsible. To develop a TEP that focuses on PROs, we adopt CMS’ structured and standardized approach. The TEP is expected to represent a diversity of perspectives and backgrounds. Members will be selected based on one or more of the following: their experience as patients; caregivers; providers (e.g., physicians, nurses, other provider stakeholders); PRO measure expertise; and methodological expertise (including psychometric testing). The TEP will have ample representation from patients and patient advocates.

For this project, TEP members will (1) review the current quality of life and recovery time measure concepts; (2) provide recommendations on their potential development; and (3) review and provide recommendations on the Patient-Reported Outcome Measurement Information System (PROMIS) and potentially other PRO measures or measure concepts identified by the TEP.

We are seeking nominations from individuals with relevant experience, expertise, and a variety of perspectives to serve on this TEP. We anticipate that the in-person meeting will take place over one to two days and will likely include multiple pre-TEP teleconference calls and additional post-TEP teleconference calls as needed. The pre-TEP teleconferences will be working sessions that will focus on review and preliminary assessment of HRQoL instruments, the PROMIS catalog of PRO tools, a recovery time measure; and other potential PRO measures that should be considered for focused discussion at the in-person meeting. TEP members’ attendance at all these meetings is required.

Project Objectives:
UM-KECC, through its contract with the Centers for Medicare and Medicaid Services (CMS), will convene a technical expert panel (TEP) to evaluate and make recommendations regarding the development of patient-reported outcome (PRO) measures.

TEP Objectives:
The TEP will be expected to:

1. Review existing health related quality of life (HRQoL) measures and recovery time measures and the PROMIS set including evaluating evidence and usability for patients and providers; address
existing testing or need for psychometric testing within the ESRD population; and data collection feasibility.

2. Make recommendations on the potential development of PRO measures including health related quality of life, recovery time, and measures derived from PROMIS item banks/domains, or potentially other measures identified by the TEP.

**TEP Requirements:**
A TEP of approximately 11-13 individuals will review potential patient-reported measure concepts and provide recommendations for measure development. The TEP will be comprised of individuals with the following areas of expertise and perspectives:

- Patient and caregiver perspectives
- Subject matter expertise: individuals with clinical (physicians, nurses, dialysis providers) and/or consumer testing expertise
- Methodological expertise: methodologists with expertise in patient-reported outcome measure development and/or psychometric testing and/or experience with health-related quality of life measurement tools, related item sets and survey methodology
- Performance measurement
- Purchaser perspective
- Health care disparities

Potential TEP members must be aware that participation on the TEP is voluntary. As such, individuals wishing to participate on the TEP should understand that their input will be recorded in the meeting minutes. Proceedings of the TEP will be summarized in a report that is disclosed to the general public. If a participant has disclosed private, personal data by his or her own choice, then that material and those communications are not deemed to be covered by patient-provider confidentiality. If patient participants (only) wish to keep their names confidential, that request can be accommodated. Any questions about confidentiality will be answered by the TEP organizers.

All potential TEP members must disclose any current and past activities that may pose a potential conflict of interest for performing the tasks required of the TEP. All potential TEP members should be able to commit to the anticipated time frame needed to perform the functions of the TEP.

**Patient Nominees:**

UM-KECC is seeking patients who can provide input on patient reported outcomes, based on their own experiences and outlooks as dialysis patients. Patients can provide unique and essential input on quality measures based on their own experience and perspective. Patient nominees should submit a completed and signed TEP Nomination Form and letter of interest as described below but are not required to submit a curriculum vitae.

**TEP Expected Time Commitment:**

- TEP members should expect to come together for two to three teleconference calls prior to the in-person meeting held May 2017, in Baltimore, MD.
- The in-person meeting May 2017 (final date to be determined).
- After the in-person meeting, additional teleconference calls are planned.

**Required Information:**
- The nomination form includes a consent and confidentiality statement.
- A letter of interest (not to exceed two pages) highlighting experience/knowledge relevant to the expertise described above and involvement in measure development.
- Curriculum vitae or a summary of relevant experience for a maximum of 10 pages.
- Patient participants are not required to submit a curriculum vitae and may elect to keep their names confidential in public documents.

If you wish to nominate yourself or other individuals for consideration, please complete the form and email it to dialysisdata@umich.edu by close of business (5:00pm ET) on February 10, 2017.

*If you have any questions, please feel free to contact me. Thank you!*

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