TO: Consensus Standards Approval Committee (CSAC)

FR: Sarah Sampsel and Suzanne Theberge

RE: Person- and Family-Centered Care – Off-Cycle Review Member Voting Results

DA: March 18, 2016

The CSAC will review the recommendation from the *Person- and Family-Centered Care (PFCC) – Off-Cycle Review* project at its March 23-24 In-Person Meeting.

This memo includes a summary of the project, the recommended measure, and public and member comments. Member voting on this recommended measure ended on February 25, 2016.

Accompanying this memo are the following documents:

1. **Person- and Family-Centered Care – Off-Cycle Review Draft Report.** The draft report has been updated to reflect the Standing Committee review of public and member comments. The complete draft report and supplemental materials are available on the project page.
2. **Comment table**. This table lists the one comment received and the Standing Committee and measure developer responses.

CSAC ACTION REQUIRED

Pursuant to the CDP, the CSAC may consider approval of one candidate consensus standard.
Person- and Family-Centered Care – Off-Cycle Review Measure Recommended for Endorsement:

- 2483: Gains in Patient Activation (PAM) Scores at 12 Months

In addition to reviewing one new measure, the Committee considered two measures (#2643 and #2653) that had previously been endorsed with a condition involving the risk-adjustment methodology. The Committee recommended that the condition of endorsement be removed for both measures after reviewing the finalized risk-adjustment methodology. The CSAC does not need to take any additional action at this time as the CSAC reviewed these two measures previously and recommended both measures for endorsement.

BACKGROUND

Ensuring that every patient and family member is engaged as partners in their care is one of the core priorities of the National Quality Strategy (NQS). Despite recent and ongoing efforts to shift the healthcare paradigm from one in which patients are passive recipients of care to one in which they are empowered to actively participate in their own care, the current state of the system has a long way to go before this shift is realized. A recent definition of person- and family-centered care put forth by NQF emphasizes the inclusivity of recipients of healthcare services and their families and caregivers:

> Person- and family-centered care is an approach to the planning and delivery of care across settings and time that is centered on collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-

being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values.

Examples of person- and family-centered care include patient and family engagement in care, care based on patient needs and preferences, shared decision-making, and activation for self-care management. Assessments and treatment should acknowledge and address medical, behavioral, and social needs and should reflect the ability or willingness of the care recipient to be an active participant in making decisions and self-advocating. The process of goal setting should be a collaborative one driven by the patient in collaboration with a primary care provider and other team members.

Due to the large number of person- and family-centered care measures, maintenance review of endorsed measures and consideration of new measures is taking place over several phases in 2014 – 2016. The Phase 1 project focused on reviewing experience with care based measures. NQF endorsed one new measure and 10 measures undergoing maintenance review. The second phase of the project, detailed in the Phase 2 project report, focused on reviewing 28 functional status measures. The third phase of the project expands the focus areas to measures of symptom burden, quality of life, shared-decision making and experience of care.

DRAFT REPORT

During the Person- and Family-Centered Care – Off-Cycle Review the Standing Committee evaluated one newly-submitted measure against NQF's standard evaluation criteria. The Committee recommended the measure for endorsement. The measure was evaluated against the 2015 version of the measure evaluation criteria.

	MAINTENANCE	NEW	TOTAL
Measures considered	0	1	1
Withdrawn from consideration	0	0	0
Recommended	0	1	1
Not recommended	0	0	0

COMMENTS AND THEIR DISPOSITION

NQF held a pre-evaluation comment period from October 21- November 05, 2015 for measure #2483: Gains in Patient Activation (PAM) Scores at 12 Months. No comments were received during this comment period. The Draft Report went out for Public and Member comment from December 14, 2015 – January 12, 2016. During this commenting period, NQF received one comment from one member organization.

Comment and Committee Response

Since only one comment was received and it did not raise any new issues, the Committee elected to consider the comment via email rather than to convene by conference call. Prior to making their decision, the Committee also reviewed the developer's response.

Comment - 2483: Gains in Patient Activation (PAM) Scores at 12 Months
The commenter raised concerns about whether metrics measured by the PAM tool can be linked to actions towards improved health.

***Developer Response*:** Over 240 articles have been published that quantify patient activation using the Patient Activation Measure® (PAM®). At least 85 percent of these studies show a statistically significant relationship between PAM scores and positive health actions, including getting preventive screening tests, immunizations, and health check ups. PAM is also a significant predictor of healthy behaviors such as healthy eating and regular exercise. These studies show that higher PAM scores are linked with better self-management of chronic conditions, including more consistent monitoring of conditions, better adherence to treatment regimens, and greater knowledge about condition and treatment options.

Many studies document that better health and clinical outcomes are associated with higher PAM scores. For example, more activated individuals are more likely to follow through on post-surgical treatment regimens and to have better functioning after joint replacement. Finally, there is evidence that those scoring higher on the PAM survey are more likely to have a primary care provider, to ask questions in the medical encounter, and to use comparative quality information in making a provider choice.

These research findings are quite robust, and include study populations from different cultures, ages, socio-economic groups, and different racial and ethnic groups. The studies referred to here are primarily from the U.S. but also from European, Middle Eastern, and Asian countries.

A bibliography of PAM studies is available at http://s3-us-west-2.amazonaws.com/insignia/Research-Studies-Using-PAM.Bibliography.pdf?mtime=20150629140537

Committee Response: The Committee continues to recommend the measure for endorsement.

NQF MEMBER VOTING RESULTS

A representative from 1 member organization voted, stating that they did not approve the measure currently specified. A comment was submitted with the vote: "The AAFP does not support a measure that requires the use of a proprietary tool. This will increase cost to our members and administrative burden." (Heidy Robertson-Cooper, American Academy of Family Physicians)

COMMITTEE RECOMMENDATIONS FOR MEASURES #2643 AND #2653

Recommend for Endorsement - Conditions Removed

- 2643: Average change in functional status following lumbar spine fusion surgery (MNCM)
- 2653: Average change in functional status following total knee replacement surgery (MNCM)

During Phase 2 of the project (2015), two measures (#2643 and #2653) were reviewed and recommended by the Standing Committee. During the Committee deliberations, it was noted that, although the measures were fully tested and use within Minnesota had begun, the risk adjustment methodology had not been finalized. In the original submission, Minnesota Community Measurement

(MNCM) provided a rationale for the lack of finalized methodology, a timeline for full collection of data, and potential strategies they were considering. During the endorsement and ratification process, NQF placed a condition on the endorsement of the measures requiring that risk adjustment be finalized and evaluated by the Committee within one year of endorsement. MNCM was able to finalize risk adjustment in October 2015 and presented their findings to the Committee at the November 13, 2015 webinar.

After discussion and consideration of the information provided by MNCM, the Committee voted to support endorsement of the measures and to remove the conditions for the annual update. These two measures are now endorsed without any conditions.

Appendix A-Measure Evaluation Summary Tables

LEGEND: Y = Yes; N = No; H = High; M = Moderate; L = Low; I = Insufficient

2483 Gains in Patient Activation (PAM) Scores at 12 Months

Submission |

Description: The Patient Activation Measure® (PAM®) is a 10 or 13 item questionnaire that assesses an individual´s knowledge, skill and confidence for managing their health and health care. The measure assesses individuals on a 0-100 scale. There are 4 levels of activation, from low (1) to high (4). The measure is not disease specific, but has been successfully used with a wide variety of chronic conditions, as well as with people with no conditions. The performance score would be the change in score from the baseline measurement to follow-up measurement, or the change in activation score over time for the eligible patients associated with the accountable unit.

The outcome of interest is the patient's ability to self-manage. High quality care should result in gains in ability to self-manage for most chronic disease patients. The outcome measured is a change in activation over time. The change score would indicate a change in the patient´s knowledge, skills, and confidence for self-management. A positive change would mean the patient is gaining in their ability to manage their health.

A "passing" score for eligible patients would be to show an average net 3-point PAM score increase in a 6-12 month period. An "excellent" score for eligible patients would be to show an average net 6-point PAM score increase in a 6-12 month period.

Numerator Statement: The numerator is the summary score change for the aggregate of eligible patients in that unit (e.g., patients in a primary care provider´s panel, or in a clinic). The change score would be calculated from a baseline score and then a second score taken within 12 months of the baseline score (but not less than 6 months). The change score is the difference between the baseline and the second score in a 12-month period. The aggregate score would be the total score for the eligible patient population. The total aggregate score could be a positive or a negative number. A "passing" score for eligible patients would be to show an average net 3-point PAM score increase in a 6-12 month period. An "excellent" score would be for eligible patients to show an average of a 6-point PAM score increase in a 6-12 month period.

Denominator Statement: All patients can be included in the denominator, except children under the age of 14 and adults with a diagnosis of dementia or cognitive impairments (based on ICD codes). Also excluded would be patients who do not have two PAM scores. Finally, we exclude all patients who are at level 4 at baseline (as they are unlikely to gain in activation over time). To be considered for evaluation, an accountable unit would need to have two PAM scores per patient (taken no less than 6 months and not more than 12 months apart) on at least 50% of their eligible patients who had two visits during that time period.

Exclusions: All patients who are at PAM level 4 at baseline, as their scores are unlikely to increase, and children under 14 and any adults who have a diagnostic code indicating dementia or cognitive impairment.

ICD Codes include:

90.0 SENILE DEMENTIA UNCOMPLICATED

290.10 PRESENILE DEMENTIA UNCOMPLICATED

290.11 PRESENILE DEMENTIA WITH DELIRIUM

290.12 PRESENILE DEMENTIA WITH DELUSIONAL FEATURES

331.83 MILD COGNITIVE IMPAIRMENT

2483 Gains in Patient Activation (PAM) Scores at 12 Months

Adjustment/Stratification:

Level of Analysis: Clinician : Group/Practice, Clinician : Team

Setting of Care: Ambulatory Care : Ambulatory Surgery Center (ASC), Ambulatory Care : Clinician Office/Clinic, Dialysis Facility, Home Health, Post Acute/Long Term Care Facility : Inpatient Rehabilitation Facility, Behavioral Health/Psychiatric : Outpatient, Ambulatory Care : Outpatient Rehabilitation, Pharmacy

Type of Measure: PRO

Data Source: Electronic Clinical Data : Electronic Health Record, Healthcare Provider Survey, Patient Reported Data/Survey

Measure Steward: Insignia Health

STANDING COMMITTEE MEETING [11/13/2015]

1. Importance to Measure and Report: <u>The measure meets the Importance criteria</u>

(1a. Evidence, 1b. Performance Gap

1a. Evidence: **Y=13 N=0** 1b. Gap: **H=6; M=4; L=2; I=1**

<u>Rationale</u>:

- The developer indicated the PAM measures an individual's knowledge, skill, and confidence, and their ability to manage their health and their health care. The rationale is that the PAM score is predictive of health behavior, clinical outcome, many measures of utilization or costly utilization, and overall cost. The underlying assumption is that high-quality care includes interventions such as coaching and support intended to increase patients' activation (ability to manage their disease), and that patients receiving such care should be gaining in their ability to self-manage over time. This is what the change in the PAM score would demonstrate.
- The proposed measure is based on examination of data from several sources. The numerator of the measure is the aggregate change in PAM score for a defined population, and the change over a 12-month period but not less than a 6-month period. The denominator is the patients in that facility or that panel who have at least 2 visits during that time period.
- Clarification of the timing of administration was requested and the developer indicated that for the measure, people need 2 scores in order to see a change. The measure requires measurement at 2 points in time; that could be over a year but not shorter than 6 months.
- The Committee had questions about the nature of the score, and the developer responded that an improvement of 3 points on a 1-100 scale is needed to pass the measure, and that an improvement of 6 points is considered excellent. During their reviews, the developer has seen that a 3-point change is related to changes in behavior. In addition, 3 points is also a reasonable level of improvement for setting a bar for how many clinicians would pass the measure. A very high level of performance would be needed to reach a change of 6 points, which is why it considered excellent.
- There was a request for specific literature supporting that a change in 3 points or 6 points leads to better outcomes. The developers indicated the citations were provided in their submission, but they will further highlight them for committee consideration.

2. Scientific Acceptability of Measure Properties: <u>The measure meets the Scientific Acceptability criteria</u>

(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)

2483 Gains in Patient Activation (PAM) Scores at 12 Months

2a. Reliability: **H-4**; **M-6**; **L-1**; **I-2** 2b. Validity: **H-1**; **M-8**; **L-2**; **I-2**

Rationale:

- The Committee agreed there was good data that were presented on individual item reliability as well as test-retest reliability. The original PAM articles provided in the submission indicated very high internal consistency reliability.
- It was noted there were no reliability or validity data presented for children, specifically for adolescents over the age of 14, who are included in the measure denominator. The Committee member questioned what was known about meaningfulness of activation for this age group specifically, since the items are cognitively difficult and may mean something very different for a child whose parent or caregiver tends to take primary responsibility for managing their health condition. The developer team indicated that quite a few studies over the years have included children (ages 12 and above) with decent samples sizes, but this data is not in the published literature. They have also asked a number of clients to offer an opinion on the measure's applicability to adolescents and whether a 14 or 15 or 16-year-old will respond as adults do. At the aggregate level, the developer stated the answer was yes. They thus believe the age range is suitable, and indicated a willingness to pull some of that data together for Committee review.

3. Feasibility: H-5; M-5; L-3; I-0

(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c.Susceptibility to inaccuracies/ unintended consequences identified 3d. Data collection strategy can be implemented)

Rationale:

- The Committee inquired as to what parts of the measure are proprietary: is the questionnaire itself proprietary, is the scoring proprietary, or is all of the above proprietary? The developer indicated all of the above are proprietary. The surveys and all the PAM versions are owned by the university and state of Oregon, and the algorithm is also proprietary. On occasion clients are permitted to have the algorithm to integrate into their systems, particularly into EMRs.
- The Committee was advised to review the licensing and other requirements for use of the survey as available on the Committee SharePoint site, and to consider cost and lack of transparence into their feasibility assessment vote.
- A member requested clarification on measure collection and who is actually responsible for contacting the patient or administrating the questionnaire, especially for the second round of surveys. The developer explained that the follow up PAM can mailed to a patient's home, administered via telephone, or via regular patient interaction in the course of a year.

4. Use and Usability: H-6; M-4; L-3; I-0

(Meaningful, understandable, and useful to the intended audiences for 4a. Public Reporting/Accountability and 4b. Quality Improvement)

Rationale:

- It was noted that the PAM tool seems to be easy to use, due to short length and the fact that it can be administered via a variety of modalities. It was noted that little was known about use in the adolescent age group.

5. Related and Competing Measures

- No related or competing measures noted.

2483 Gains in Patient Activation (PAM) Scores at 12 Months

Standing Committee Recommendation for Endorsement: **Y-11**; **N-2**

- Some Committee members noted concerns with the proprietary nature of the PAM, as well as a wish to see more data and more of the calculation algorithm in order to more fully understand the linkage between the measure and feasible processes of care.

6. Public and Member Comment

- One comment was received during the post-evaluation Public Comment period. The commenter questioned if sufficient evidence exists to conclude that the knowledge, skills, and attitudes measured by PAM relate directly to action taken for health improvements?
- The developer submitted the following response:
  - Over 240 articles have been published that quantify patient activation using the Patient Activation Measure® (PAM®). At least 85 percent of these studies show a statistically significant relationship between PAM scores and positive health actions, including getting preventive screening tests, immunizations, and health checkups. PAM is also a significant predictor of healthy behaviors such as healthy eating and regular exercise. These studies show that higher PAM scores are linked with better self-management of chronic conditions, including more consistent monitoring of conditions, better adherence to treatment regimens, and greater knowledge about condition and treatment options.

    Many studies document that better health and clinical outcomes are associated with higher PAM scores. For example, more activated individuals are more likely to follow through on post-surgical treatment regimens and to have better functioning after joint replacement. Finally, there is evidence that those scoring higher on the PAM survey are more likely to have a primary care provider, to ask questions in the medical encounter, and to use comparative quality information in making a provider choice.
    These research findings are quite robust, and include study populations from different cultures, ages, socio-economic groups, and different racial and ethnic groups. The studies referred to here are primarily from the U.S. but also from European, Middle Eastern, and Asian countries.
    A bibliography of PAM studies is available at http://s3-us-west-2.amazonaws.com/insignia/Research-Studies-Using-PAM.Bibliography.pdf?mtime=20150629140537
- The Committee agreed this response was satisfactory and did not change their recommendation.

7. Consensus Standards Approval Committee (CSAC) Vote: Y-X; N-X; A-X

8. Board of Directors Vote: Y-X; N-X

9. Appeals