

Summary of Person and Family Committee (PFC) Input for Wave 2 Episode-Based Cost Measure Development

MACRA Episode-Based Cost Measures

October 2018

Overview

The Centers for Medicare & Medicaid Services (CMS), in conjunction with Acumen, LLC and Westat, convened a Person and Family Committee (PFC) to solicit feedback from Medicare beneficiaries and caregivers on their perspectives regarding episodes of care and clinician cost performance. The role of the PFC throughout Wave 2 of measure development in this project (April to December 2018) has been sharing their experience to help inform (i) selection of episode groups for development, and (ii) methodological decisions in constructing measures that will provide meaningful feedback on cost measure performance to clinicians. Acumen has gathered this input to bring to Clinical Subcommittees (CS) and workgroups who consider this input, along with empirical analyses and their clinical judgment, in building out each component of the episode-based cost measures. CS and workgroup members also had the opportunity in each meeting to identify questions for the PFC to provide guidance to their input (e.g., members were often interested in hearing more about post-discharge planning from the patient perspective so that they could take this into consideration for identifying a post-trigger period or assigned services). For more information about the overall measure development process, please see the [Measure Development Process](#) document, which provides the project background and details of the process for developing the 11 episode-based cost measures.¹ The measure specifications for each of the 11 measures are available on the [MACRA Feedback Page](#):

- [Measure Codes List \(April 2019\)](#): contains the medical codes used in constructing each of the 11 episode-based cost measures.²
- [Cost Measure Methodology \(April 2019\)](#): details the measure methodology for each of the 11 episode-based cost measures.³

Across four rounds of PFC discussions in 2017-18, we have completed more than 100 in-depth discussions with Medicare beneficiaries and caregivers.

- Initial conversations with the PFC in June 2017 focused on the broad concepts of health care quality and value and understanding episode groups from the person and family perspectives. This high-level perspective helped shape the process of bidirectional feedback between the Clinical Subcommittees (and workgroups) and the PFC for the beginning of Wave 2 of measure development.
- We then focused on patient and caregiver perspectives on the types of episode groups that should be prioritized for development (March 2018). PFC input was used to inform Clinical Subcommittee (CS) members' selection of Wave 2 episode groups, along with feedback from a Technical Expert Panel (TEP).⁴
- In June 2018, our discussions with the PFC focused on pre- and post-trigger services, attribution of clinicians, and services perceived as aiding recovery or helping to avoid unnecessary costs and complications. This round of PFC input was broken into five separate buckets of medical treatments (i.e., acute hospitalizations, urgent surgeries, scheduled surgeries, end-stage renal disease and dialysis, and hospitalizations for Psychoses/Related

¹ CMS, "Episode-Based Cost Measure Field Testing: Measure Development Process", MACRA Feedback Page, <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/2018-measure-development-process.pdf>.

² CMS, "Measure Codes List", MACRA Feedback Page, <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/2019-revised-ebcm-measure-specs.zip>. Each of the 11 documents are within the zip file and are labeled with "2019-04-10-codes-list-" in the beginning of the filename.

³ CMS, "Cost Measure Methodology", MACRA Feedback Page, <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/2019-revised-ebcm-measure-specs.zip>. Each of the 11 documents are within the zip file and are labeled with "2019-04-10-ebcm-methods-" in the beginning of the filename.

⁴ CMS, "MACRA Episode-Based Cost Measures Technical Expert Panel Webinar March 23, 2017 Summary Report" (this is the "MACRA_Episode_Based_Cost_Measures_TEP_Summary_Mar2017.pdf" file within the following zip file: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/MACRA-Episode-Based-Cost-Measures-.zip>)

Conditions) for the 11 episode-based cost measures. The input from these discussions were shared with workgroup members prior to the workgroup in-person meetings in June 2018 so they could consider these findings as they discussed and provided input on measure specification.

- During the final round of discussions with the PFC in Wave 2, we conducted in-depth interviews with PFC members who had specific experience with one of the Wave 2 episode groups (September-October 2018). This document compiles that input which was shared with workgroup members who considered these findings, alongside stakeholder feedback from a national field testing period (October 2018) and results of testing analyses, in making refinements to the measures. As guided by CS and workgroup member questions, the PFC discussions focused on:
 - (i) Pre- and post-trigger periods and treatment received therein;
 - (ii) Services provided by and costs incurred by various clinicians, including those seen before and after the trigger event;
 - (iii) PFC members' perception of value in health care; and
 - (iv) Services perceived as aiding recovery or helping to avoid unnecessary costs and complications.

This document summarizes the findings related to medical treatments for the following episode-based cost measures that was provided to the workgroup members in October 2018:

- [Acute Kidney Injury Requiring New Inpatient Dialysis](#)
- [Elective Primary Hip Arthroplasty](#)
- [Femoral or Inguinal Hernia Repair](#)
- [Hemodialysis Access Creation](#)
- [Inpatient Chronic Obstructive Pulmonary Disease \(COPD\) Exacerbation](#)
- [Lower Gastrointestinal Hemorrhage](#)
- [Lumbar Spine Fusion for Degenerative Disease, 1 – 3 Levels](#)
- [Lumpectomy, Partial Mastectomy, Simple Mastectomy](#)
- [Non-Emergent Coronary Artery Bypass Graft \(CABG\)](#)
- [Psychoses/Related Conditions](#)
- [Renal or Ureteral Stone Surgical Treatment](#)

Acute Kidney Injury Requiring New Inpatient Dialysis

For this measure, nine PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 There was wide variability in the pre-trigger window for PFC members with AKI.

- Nearly all PFC members noted that either their primary care provider, or their nephrologist was responsible for their treatment leading up to the diagnosis of AKI. However, in one instance where the PFC member needed to be airlifted to the hospital, he noted that it was the attending physician at the hospital.
- Although not all PFC members immediately saw a nephrologist at the onset of symptoms, most eventually met with a nephrologist to discuss their symptoms.
- When asked about being able to do “usual things” like bathing, dressing, or visiting a doctor’s office in the weeks leading up to the diagnosis of AKI, responses were mixed across the PFC members with some being quite able and others suffering severe physical limitations.
- The length of time leading up to the AKI trigger event ranged from hours to months, depending on the symptoms experienced and the event that led to the kidney injury.
- Most PFC members went to the emergency room, or an urgent care center when becoming severely symptomatic.

2. PFC Feedback: Trigger Event

2.1 ‘Flu-like symptoms’ were common trigger events for PFC members with AKI.

- While some PFC members had a specific event that brought them to the hospital, many noted progressive “flu-like” symptoms.

2.2 Nephrologists were at the center of AKI episodes.

- All PFC members reported receiving care from a nephrologist. Surgeons and other clinicians were often involved as well, depending on the PFC member’s symptoms.
- In most cases, it was reported that there was a joint health care decision made with the nephrologist to proceed with dialysis treatment. In a few instances, PFC members reported that the physician made the decisions unilaterally as they were too ill to participate in decision-making.
- When multiple physicians were involved, all PFC members reported good coordination with physicians communicating relevant information to each other, and to the PFC member regularly.

2.3 PFC members’ kidney function was tested throughout their episodes.

- Many members reported having kidney biopsies or ultrasounds on their kidneys. Other tests included breathing tests, blood tests, urinalyses, MRIs, and vascular scans.
- Although some tests, like ultrasounds, were conducted more than once, they were not viewed as being duplicative or unnecessary. Instead, PFC members noted they were done multiple times to monitor progression of kidney function.

2.4 PFC members reported their primary goal was to survive the episode.

- The primary concern for many of the PFC members was simply just to live.
- Many PFC members noted that there was nothing that the clinical teams could have done to help alleviate their concerns.

2.5 Involvement in discharge planning led to better overall rating of health care coordination.

- PFC member involvement in post-episode treatment planning varied within the group. Those who were more involved in the discharge planning typically had a better overall rating of how well their health care team worked together.

3. PFC Feedback: Post-Trigger Window and Services

3.1 Nephrologists were involved throughout the episode of care.

- All PFC members noted that their nephrologist was involved, if not in charge of their post-trigger care.
- Others involved in the post-trigger care include vascular surgeons, immediately following surgery, and primary care providers and hematologists thereafter.
- Long-term care following AKI was consistently reported as being provided by the members' nephrologists.

3.2 In situations where AKI occurred after surgery, follow-up care included the surgeon and sometimes involved physical therapy or occupational therapy.

- Virtually all PFC members had a follow-up appointment with their surgeon shortly after the surgery to ensure the wounds were healing properly.
- Many members had some type of physical and/or occupational therapy, or were given discharge instructions to help with rehabilitation.
- While the majority of PFC members went home following their episodes, a small number spent several weeks in the hospital recovering.

4. PFC Feedback: Value and Quality

4.1 Most PFC members rated their quality and value of care as excellent.

- Overall, PFC members rated their overall care, along with the care teams' understanding of their personal situations, as either very good, or excellent.
- Nearly all PFC members rated the quality and value of care received as excellent. The health care delivery areas noted for improvement were more availability of physicians, better communication with, and between, physicians, and improving bedside manner.

4.2 Communication was key to PFC assessment of health care quality.

- Some PFC members thought they would know if the care they were receiving was of low quality and noted that a lack of communication and overall decline of health were two ways to know if care was sub-standard.
- Only one member noted that he would expect to pay more for higher quality care. Others noted that cost and quality should not be directly correlated. One member also noted that she would expect Medicare to pay the physician less for lower quality care.

Elective Primary Hip Arthroplasty

For this measure, eight PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 Broad agreement among PFC members that worsening symptoms drove the need for increased care during the pre-trigger window.

- Many PFC members reported receiving regular care for hip pain from a primary care provider, and as symptoms worsened, they were referred to an orthopedist for additional treatment and ultimately, operative planning.
- PFC members reported varying ability to do “usual things” like bathing, dressing, or visiting a doctor’s office at the onset of symptoms; however, by the time they decided to have surgery, most reported having some or a lot of difficulty with “usual things” and severe pain.
- Most PFC members reported having imaging of their hips, as well as visits with a primary care provider and orthopedist, during the pre-trigger window.

2. PFC Feedback: Elective Surgery

2.1 Most PFC members reported working with their primary care provider to decide when and with whom to have surgery.

- PFC members reported talking to their physicians about their level of pain, quality of life, and age when comparing treatment options and deciding to have surgery.
- Some PFC members also considered a surgeon’s level of experience with the procedure when selecting a surgeon for their procedure.

2.2 The orthopedic surgeon and related team led care delivery in the hospital, though other providers were involved.

- All PFC members reported receiving care from an orthopedic surgeon and many also reported receiving substantial services from members of the surgeon’s team.
- Many PFC members reported receiving care from specialists (e.g., cardiologist, dentist) as part of the pre-operative clearance process.

2.3 Imaging scans and cardiovascular tests were conducted in preparation for surgery.

- Many PFC members noted that the care team ordered imaging scans of their hip, cardiovascular stress tests, and blood tests in advance of the surgery.
- For some PFC members, these tests were conducted at outpatient facilities, and for others, the testing was done in the hospital either on an outpatient basis or once admitted for surgery.

2.4 Health care goals included reduced pain and improved quality of life.

- Most PFC members reported severe or debilitating pain in their hips, and they hoped that surgery would result in pain reduction and increased mobility.

2.5 Discharge planning was seen as a critical step to recovery and avoiding future complications, including risks of infection and blood clots.

- Many PFC members reported working with the surgeon or a nurse to learn about wound care, physical therapy exercises, medications, and ways to avoid or identify a complication, such as a surgical site infection or blood clot.
- Most PFC members reported that when the health care team had an excellent understanding of their personal situation, this led to appropriate post-discharge care either in a rehabilitation facility or at home with support from family and friends or home health aides.

3. PFC Feedback: Post-Trigger Window and Services

3.1 Most PFC members received physical therapy and outpatient follow-up visits with the surgeon.

- Physical therapy was provided in the hospital prior to discharge. PFC members also reported receiving post-discharge physical therapy in outpatient facilities, rehabilitation facilities, or at home with a home health aide.
- PFC members received routine follow-up visits with the orthopedic surgeon throughout the post-trigger period, and half of PFC members reported routine follow up visits after the 90-day post-trigger window (e.g., 6- and 12-month follow-up visits).

3.2 The orthopedic surgeon often led post-discharge care, but the physical therapy team played a substantial role.

- Many PFC members reported that the orthopedic surgeon was in charge of the overall care plan, and a few PFC members stated that the physical therapists deserved “the credit” for their recovery and rehabilitation.

4. PFC Feedback: Value and Quality

4.1 Some PFC members reported that the quantity of care or communication they received could have been improved.

- Although they reported receiving high quality care, some PFC members noted that their post-operative strength and mobility was below expectations, and they believed that they could have benefited from additional physical therapy.
- Some reported that better communication about managing post-operative pain, the importance of physical therapy, and wound care would have been helpful because their recovery was more difficult than expected.

4.2 Many PFC members did not consider the cost or value of the care they received because information on how to assess value and cost was not available to them.

- Many PFC members reported that they were not certain they would know if care was complete or of “high value” and believed they needed to trust the clinician to provide the right care at the right time.
- Many PFC members reported that they did not consider the costs of care because their surgery was covered by insurance.

Femoral or Inguinal Hernia Repair

For this measure, six PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 The amount of time from onset of symptoms to surgery varied among PFC members.

- The majority of PFC members reported that they initially saw their primary care physician. Members were then recommended to a surgeon to schedule the surgery.
- The length of time from the onset of symptoms to the actual surgery ranged from a few weeks to nearly one year.
- At the onset of symptoms relating to the hernia, PFC members reported being able to do “usual things” like bathing, dressing, or visiting a doctor’s office with some or no difficulty.
- Upon diagnosis, nearly all PFC members immediately scheduled their surgery.

2. PFC Feedback: Trigger Event

2.1 Shared decision-making led to surgery for PFC members.

- Most PFC members noted that it was a combination of increased pain and the diagnosis from their primary care provider that led to their decision to undergo surgery.
- Nearly all members noted that the decision for surgery was a shared decision made with their primary care provider.

2.2 Primary care providers delivered the initial diagnoses and then referred members to surgeons.

- Nearly all PFC members were diagnosed by their primary care providers. Members were then referred to surgeons who would perform the hernia surgeries.
- Prior to surgery, all PFC members underwent basic lab work. A few members also had imaging tests.

2.3 PFC members largely entered into surgery without any concerns.

- Nearly all PFC members went into surgery without any concerns as they believed the procedure was a “basic surgery.”
- Several members also noted that their surgeon or the hospital was highly rated, therefore they believed they were “in good hands.”
- One member noted a concern that the hernia repair would not hold.
- Alternative treatment options were not considered. Some noted that they felt surgery was the only option for their condition.

2.4 Minimal discharge planning reported by PFC members.

- PFC members reported that due to the type of episode, there was little discharge planning. In most cases, members were only told when to return for a post-operative check-up to get their stitches removed.
- Despite the lack of post-operative planning, when asked to what extent they were involved in decisions about care following their surgery, all PFC members replied “a great deal.”

3. PFC Feedback: Post-Trigger Window and Services

3.1 PFC members were discharged home to heal.

- All PFC members were discharged to their homes within hours of their surgery. Their instructions were to “lay low” until their wounds had enough time to heal.

3.2 Post-surgical care attributed to the surgeon/surgical team.

- All PFC members attributed responsibility for post-surgical care to their surgeon/surgery team.
- Members reported initial follow-up appointments with the surgeon occurred between one and two weeks post-surgery. Additionally, some members also followed up at four weeks post-surgery.
- Some PFC members also mentioned seeing their primary care providers following their surgeries. All reported being pleased with the coordination and sharing of information and records between the surgeon and the primary care provider.

4. PFC Feedback: Value and Quality

4.1 Members had few concerns about quality or value of care.

- Leading up to their surgeries, none of the PFC members had concerns about quality of care.
- Many reported that they would know if the care they were receiving was of low quality based on their prior health care experiences and/or the results of the hernia surgery.
- Nearly all PFC members rated their overall quality of care as excellent, including one member who reported that her surgery “didn’t take” – she attributed this result to her abdominal weakness and felt it could not have been avoided.
- Virtually all PFC members also rated the overall value of the care they received as excellent. One PFC member noted a concern about cost of care due to a previous negative experience with a “cheap health plan.” Other members reported that they did not have any concerns about cost of care or value of services received.

Hemodialysis Access Creation

For this measure, nine PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 PFC members were typically under the care of a nephrologist, and coordinated with the nephrologist and a vascular surgeon after deciding on a permanent hemodialysis access.

- PFC members typically received care from a nephrologist in the period leading up to their hemodialysis access creation.
- Some PFC members experienced symptoms of deteriorating kidney function for a decade or more before hemodialysis access creation. In other cases, symptoms started less than a year before dialysis. While symptoms may have started years in advance, the decision to have surgery was typically made within two to three months of the hemodialysis access creation procedure.
- PFC members' ability to do "usual things" like bathing, dressing, or visiting a doctor's office ranged from "no difficulty" to "could not do at all" before hemodialysis access creation. From onset of symptoms to decision to have hemodialysis access creation, almost all respondents reported their functional status stayed the same or worsened.
- Some PFC members explored peritoneal dialysis prior to the hemodialysis access creation. Some PFC members indicated that they required a dialysis catheter placement because they needed to start dialysis urgently before the creation of a more permanent hemodialysis access (arteriovenous fistula or graft).

2. PFC Feedback: Trigger Event

2.1 PFC members reported they made the decision for a permanent hemodialysis access in conjunction with the nephrologist.

- Almost all PFC members reported they either made the decision to have dialysis with their nephrologist or their nephrologist made the decision for them.

2.2 The vascular surgeon was primarily responsible for the hemodialysis access creation.

- PFC members reported that the vascular surgeon was most responsible for the hemodialysis access creation. PFC members were referred to a vascular surgeon by their nephrologist after deciding that hemodialysis access creation was the next step in their care.
- Almost all PFC members recalled having a "vein mapping" procedure prior to the hemodialysis access creation. Most PFC members mentioned receiving lab tests before the hemodialysis access creation.

2.3 PFC members had minimal concerns with the hemodialysis access creation procedure, but were concerned about how having a fistula or graft would affect them.

- PFC members reported few to no concerns with the procedure itself. They were most concerned with the risk of death if they did not have the dialysis treatments themselves. Additionally, PFC members expressed concern about the risk of infection if the fistula or graft was not placed.
- After the hemodialysis access creation, PFC members shared that they took precautions to care for their fistula or graft, such as avoiding injury to the post-surgical site.
- Some PFC members experienced complications post-surgery. Multiple PFC members had follow-up procedures outside of the post-trigger period to revise the fistula or to create a new hemodialysis access port due to the initial port failing to mature. One PFC member had to have his fistula revised within the post-trigger period, but did not view this as a complication, and referred to it as a "tune-up."

2.4 PFC members did not feel adequately prepared for the lifestyle changes that would accompany hemodialysis access creation.

- Some PFC members wanted additional education around caring for their fistula, receiving dialysis, and lifestyle changes needed as a result of their condition.
- Multiple PFC members were not aware of limitations that follow hemodialysis access creation, such as not being able to lift heavy objects.
- Some PFC members felt they did not receive enough education around what to expect after the hemodialysis access creation. However, most reported having support for their ongoing dialysis (e.g., access to a dietitian, a social worker to help navigate health insurance).

3. PFC Feedback: Post-Trigger Window and Services

3.1 Most PFC members quickly recovered after hemodialysis access creation.

- While most PFC members went home within hours of the hemodialysis access creation, a few members reported hospital stays prior to being discharged to home.
- Multiple PFC members were able to return to work and “usual activities” within a day of the hemodialysis access creation, although they did note some limitations such as not being able to lift heavy objects.

3.2 PFC members reported that their vascular surgeon, nephrologist, and dialysis center staff led aspects of their care after the hemodialysis access creation.

- Responsibility for the post-trigger window was shared between the vascular surgeon, nephrologist and the dialysis center staff. After the fistula matured, the nephrologist and dialysis center staff led care related to dialysis.
- Many PFC members had a follow-up visit with a vascular surgeon to ensure that the fistula was maturing. The vascular surgeon had a minimal role after the fistula matured, unless there were complications.

4. PFC Feedback: Value and Quality

4.1 While PFC members considered the quality of care received to be excellent, some PFC members did note areas for improvement.

- PFC members reported that their care was of “excellent” quality.
- PFC members noted several potential areas for quality improvement, including better pain management and increased education about the procedure and necessary care afterwards.

4.2 PFC members largely did not consider the costs of hemodialysis access creation.

- Few PFC members were concerned about the cost of their hemodialysis access creation, as the costs of the procedure were covered by Medicare and/or other insurers.

Inpatient Chronic Obstructive Pulmonary Disease (COPD) Exacerbation

For this measure, seven PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 Broad agreement among PFC members that acute hospitalization for COPD exacerbation had no pre-trigger window or services.

- While many PFC members reported getting regular care from a primary care provider and/or a pulmonologist leading up to the COPD exacerbation, they described the exacerbation onset as occurring without warning.
- Most reported being able to do “usual things” like bathing, dressing, or visiting a doctor’s office with some or little problem in the weeks leading up to the exacerbation, then experiencing a sudden change in breathing ability leaving them completely unable to do “usual things.”
- Most PFC members were taken by ambulance to a hospital for treatment.

2. PFC Feedback: Acute Hospitalization

2.1 Initial services at the hospital were delivered in an urgent manner with little input from the PFC member.

- PFC members reported being scared and in some cases, worried about dying when they first arrived at the hospital. Given severely limited breathing abilities, they often reported being only minimally involved in their care and health care decision-making until their condition was stabilized.

2.2 Hospital pulmonologist and related team led care delivery in the hospital, though other providers were often involved.

- All PFC members reported receiving care from pulmonologists in the hospital and felt the pulmonologist and “breathing team” led care delivery in the hospital. This was sometimes, but not always, a pulmonologist that the member had previously or regularly seen for care.
- Many members, though not all, also reported receiving care from a cardiologist while receiving treatment for their COPD exacerbation.
- Few members also saw other health care providers, including allergists.

2.3 Breathing tests were conducted upon arrival at hospital and again at regular intervals during the hospitalization.

- All PFC members reported that tests were conducted to assess breathing function upon arrival at the hospital. These tests were repeated regularly while the PFC members were in the hospital and all reported at least one follow-up set of tests prior to discharge.

2.4 Avoiding future hospitalizations due to COPD and “getting back to normal life” were important goals.

- Most PFC members had multiple exacerbations over the course of several years. Avoiding the need for acute hospitalization was described as a high priority.
- PFC members reported a strong desire to get back home, back to work (in some cases), and back to “normal life,” even if that required some at-home treatments post-discharge.

2.5 Discharge planning was seen as a critical step to avoiding future exacerbations.

- Many PFC members reported working with a nurse and/or social worker to plan for discharge and self-care at home.
- Some members reported receiving tips at discharge to avoid exacerbations, including managing breathing in cold weather and keeping ready access to a rescue inhaler.
- Some members had to integrate new or increased at-home treatment; some also had to obtain equipment to support at-home treatment such as a nebulizer.
- PFC members who were facing new or increased at-home treatments were reliant on support from social workers and other staff to help them access needed equipment and to learn appropriate techniques.

3. PFC Feedback: Post-Hospital Care

3.1 Follow-up care received from pulmonologist soon after discharge.

- Most PFC members reported receiving follow-up care from a pulmonologist three to four times per year post-hospital discharge. Directly following hospital discharge, this care was sometimes delivered by the pulmonologist

seen in the hospital, but often it was another pulmonologist with which the PFC member may or may not have had an existing relationship.

- After hospitalization, most PFC members reported seeing their primary care provider for recovery and rehabilitation, though they thought some of this care after a few weeks post-discharge as being unrelated to the acute hospitalization.

3.2 “Regular” pulmonologist and primary care provider both reported as leading care delivery post-discharge.

- Many PFC members reported that the pulmonologist or primary care provider they saw regularly to manage symptoms of COPD led care delivery post-hospital discharge.

4. PFC Feedback: Value and Quality

4.1 Some PFC members reported that the quality of care they received could have been improved.

- Improved communication with their providers and more coordination between inpatient and outpatient providers were the most commonly noted areas for improvement in quality of care received.
- Many PFC members reported that they were not certain they would know if care was complete or of “high value” and felt they needed to trust the clinician to provide the right care at the right time.

4.2 Access to clinicians and time spent with clinicians was seen by PFC members as a proxy for value.

- Costs that were not out-of-pocket for the PFC member were rarely of concern.
- Value of care was often measured in terms of how much PFC members reported trusting their clinicians. Trust was earned through time spent with the PFC member and how much they felt their voices were being heard.

Lower Gastrointestinal Hemorrhage

For this measure, five PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 Some PFC members experienced symptoms and received pre-trigger services prior to diagnosis.

- Many PFC members reported having symptoms (e.g., bleeding, tarry stool) during the days or weeks prior to acute care. Some received several rounds of testing prior to diagnosis, while others did not see a clinician before presenting at the hospital.
- Among members who saw a clinician for symptoms, all reported seeing their primary care provider.
- Some PFC members reported having difficulty being able to do “usual things” like bathing, dressing, or visiting a doctor’s office in the days leading up to the episode, while other noted the symptoms but reported no change to functional status.

2. PFC Feedback: Trigger Services

2.1 Many PFC members reported that the gastroenterologist had a major role in decision-making after diagnosis.

- Some members reported being distressed or in some discomfort when they presented for acute care and, as a result, were not fully engaged in decision-making regarding treatment. Other PFC members reported being engaged in decision-making, but noted that pre-procedure anxiety made them less engaged than they might otherwise have been.
- Many PFC members reported that it was important to have treatment soon after diagnosis because they were concerned that risk of death was high if they did not receive diagnosis and appropriate care.

2.2 The gastroenterologist led care delivery in the hospital, though other providers were involved.

- All PFC members reported receiving care from a gastroenterologist, and many also reported receiving substantial services from a hospitalist.
- Most PFC members reported very good or excellent coordination between the hospital and primary care providers. For example, primary care providers shared medical records and were involved in planning for post-discharge care.

2.3 Diagnostic tests were conducted upon arrival at the hospital.

- All PFC members reported that tests were conducted to diagnose their lower GI bleed. These tests often included x-rays, CT scans, and rectal examinations performed in the emergency department.
- PFC members reported that imaging and testing services may have been repeated if diagnosis took multiple days or the care team was waiting on other co-occurring conditions to be “under control” before proceeding with treatment.

2.4 PFC members reported mixed experiences with discharge planning and complications.

- Some PFC members received written instructions for post-discharge care, and some discussed the importance of follow up visits with a primary care provider and their medication lists with their care team. Some members reported little in the way of discharge planning or future care planning.

3. PFC Feedback: Post-Hospital Care

3.1 Follow-up care was received from a primary care provider soon after discharge.

- Most PFC members reported receiving follow-up care from their primary care provider within one week of hospital discharge. The initial post-discharge check-up was sometimes followed by weekly or bi-weekly check-ups for the 4-6 weeks following discharge.
- Some PFC members reported that the primary care provider led follow up care, whereas others reported that the hospitalist or gastroenterologist led or was significantly involved in post-discharge care.
- Virtually all PFC members reported being able to do “usual things” like bathing, dressing, or visiting a doctor’s office with little or no difficulty post-discharge.

4. PFC Feedback: Value and Quality

4.1 Most PFC members rated the quality and value of their care as very good or excellent.

- Nearly all PFC members rated the quality and value of care received as very good or excellent. Despite the high ratings, some PFC members wished that they were diagnosed and treated sooner or that they received more follow up care from the gastroenterologist.

4.2 Access to clinicians and symptom reduction were seen by PFC members as measures of value.

- Where costs were covered by Medicare and, if applicable, supplemental insurance, beneficiaries infrequently thought about the costs of treatment.
- Value of care was often measured in terms of how quickly PFC members were diagnosed and received care to address their symptoms.

Lumbar Spine Fusion for Degenerative Disease, 1 – 3 Levels

For this measure, four PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 Broad agreement among PFC members that increasing pain drove the need to prepare for lumbar spine fusion surgery.

- Many PFC members reported receiving ongoing care for back pain from an orthopedist or primary care provider, and as symptoms worsened, they were referred to an orthopedist for additional health care services and ultimately pre-operative care.
- PFC members reported some, to a lot of difficulty doing “usual things” like bathing, dressing, or visiting a doctor’s office at the onset of symptoms; however, by the time they decided to have surgery, all reported having severe pain as well as a lot of difficulty with “usual things.”
- All PFC members reported having imaging during the pre-trigger window. Often images were used to monitor disc degeneration and assess applicability of various treatment options. Many PFC members also reported having discograms.

2. PFC Feedback: Elective Surgery

2.1 Most PFC members reported working with their orthopedist or primary care provider to decide when to have surgery.

- PFC members reported talking to their physicians about their level of pain, mobility, and quality of life when deciding to have surgery.
- All PFC members had undergone previous less invasive procedures to address disc degeneration. Most perceived spinal fusion as the surgery of “last resort” to address reoccurring or chronic back pain.
- The decision to proceed with spinal fusion was typically made about one to two months in advance of the actual surgery.

2.2 The orthopedist led care delivery leading up to the surgery, though other providers were involved.

- All PFC members reported receiving care from an orthopedist to prepare for surgery. Many also reported receiving substantial services from members of a surgical team, including an anesthesiologist.

2.3 Health care goals included reduced pain and improved quality of life.

- Prior to surgery, PFC members reported severe or debilitating back pain that in some cases limited their ability to work. They hoped that spinal fusion would result in pain reduction and increased mobility.
- All PFC members reported being concerned that the surgery would not be effective in reducing their pain. Most also reported fearing loss of mobility or even loss of ability to walk post-surgery.
- One PFC member sought counseling to address his pre-surgery fears and noted that he wished the surgeon had included the counselor in care planning prior to the surgery.

2.4 Engagement in discharge planning was mixed.

- Some PFC members reported working with the surgeon or a nurse in planning for physical therapy and overall rehabilitation. Other members did not recall much, if any, discharge planning and believed their post-operative care and rehabilitation was suboptimal.
- PFC members were mixed about the degree to which they thought their health care team had an understanding of their personal situation. Some members felt their situations (e.g. living alone with little support) were not adequately considered in planning for their recovery; whereas, others received inpatient rehabilitative care or support from a home health aide.

3. PFC Feedback: Post-Trigger Window and Services

3.1 Most PFC members received physical therapy and outpatient follow-up visits with the surgeon.

- All PFC members reported receiving physical therapy post-surgery. While some received services in an inpatient rehabilitation facility, others received therapy in outpatient clinics or at home. One member reported initially receiving services at home, but found the therapy “too intense” and transitioned to an outpatient clinic for further therapy services.

- All PFC members saw their surgeon (or surgeon's team) following hospital discharge (e.g. 2 weeks, 1-2 months, 6 months, and finally at one year post-surgery).
- Some PFC members were fitted for a corset post-surgery. The stated purpose of the corset varied as did the length of time members reported wearing the corset.

3.2 PFC members reported that the orthopedic surgeon led post-discharge care.

- Many PFC members reported that they thought the surgeon could have done more to coordinate their care with other clinicians, including physical therapists and primary care providers. One member even suggested that he thought his nerve damage could have been avoided if the surgeon had checked in on his recovery more regularly.
- Those who saw the surgeon him/herself for check-ups versus seeing another member of the team (e.g. the physician assistant) reported higher ratings for the care received.
- Most PFC members reported a moderate level of involvement in post-procedure decision-making. Some acknowledged being unable to participate fully due to the effects of the pain medications.

4. PFC Feedback: Value and Quality

4.1 Some PFC members reported that the quality of care that they received could have been improved.

- Although they reported receiving "good" quality care, some PFC members noted that their post-operative mobility was below expectations, and their long-term health was compromised in unanticipated ways, including having nerve damage.
- Some members believed that they could have benefited from additional information prior to surgery, others noted that they wished they had consulted with a neurosurgeon.

4.2 Many PFC members did not consider the cost or value of the care they received because they had inadequate information.

- Most PFC members reported that at the time of the hospitalization and initial recovery, they were not certain they would know if care was complete or of "high value." Several members however thought that in the years that followed the surgery, they would know if they had received quality services, based on long-term mobility and pain reduction.
- Many PFC members reported that they did not consider the costs of care because their surgery was covered by insurance. One member reported being concerned about the cost of the corset as well as the related costs (e.g. fitting of the corset and body socks).

Lumpectomy, Partial Mastectomy, Simple Mastectomy

For this measure, five PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 PFC members were able to receive timely, step-wise diagnoses.

- Most PFC members discussed seeing their primary care providers and/or gynecologists for regular check-ups or when they first experienced symptoms.
- After receiving a breast cancer diagnosis some PFC members described getting a second opinion and/or meeting with surgeons and oncologists in addition to their primary care providers.
- PFC members described having surgery within one to two months after their diagnosis.
- Nearly all PFC members described being able to do “usual things” with no difficulty during the pre-operative time.
- Nearly all PFC members also reported that they had a mammogram and needle biopsy performed as part of their diagnostic services. Prior to surgery they had other pre-operative tests such as blood work.

2. PFC Feedback: Trigger Event

2.1 PFC members were engaged in the decision to either have a lumpectomy or mastectomy.

- PFC members reported that either they alone made decisions about their care or they made decisions along with the health care provider.
- Members described having to decide whether to have a lumpectomy with or without chemotherapy or radiation therapy, or a more invasive mastectomy. PFC members who chose to have a lumpectomy also described having lymph node surgery to check for the extent of cancer. For some, the lymph node surgery was performed at the same time as the lumpectomy, but for others, it was performed in a follow-up procedure.

2.2 Once PFC members settled on a treatment plan, the surgeon was responsible for care.

- PFC members identified the surgeon as the lead clinician during the hospitalization; though primary care providers and oncologists were also involved in care associated with the surgery.
- About half the PFC members felt as if their surgeon and primary care provider were communicating well with one another; the other half reported that communication and coordination could be improved.

2.3 PFC members wanted to ensure the surgery removed their cancer, but were not always aware of complications associated with more invasive methods.

- PFC members reported that their primary goal was to be cancer-free. A secondary goal was to identify the least invasive though still effective treatment possible. Some PFC members described fears of recurrence.
- Most PFC members felt they were involved in their care a great deal, and led the team in developing a treatment and recovery plan.
- Members who had a lumpectomy all reported going home on the day-of or the day after the surgery. Those who had a mastectomy required some inpatient rehabilitation, and many faced complications post-surgery.
- In retrospect, some PFC members said they would have opted for less invasive surgeries and/or requested more information from the physicians in order to have a better understanding of their diagnosis and risks.

2.4 Post-surgery rehabilitation steps were usually clear.

- Appointments with oncologists were established for all PFC members who had a lumpectomy or when the risk of cancer persisted after the surgery.
- For PFC members who underwent a mastectomy, the care plan was reported to include hospitalization followed by residential rehabilitation and consultation with a plastic surgeon.
- Most PFC members who were discharged home after their surgery were able to manage their own wound care.

3. PFC Feedback: Post-Trigger Window and Services

3.1 Most PFC members reported that the surgeon was leading care delivery immediately following surgery.

- During the time immediately following the surgery, most PFC members reported that the surgeon was leading care delivery with support from the oncologist and broader cancer care team.
- For members receiving additional cancer treatments, after the surgical site healed, the oncologist resumed the lead role in care planning and delivery.

- PFC members who underwent a mastectomy reported being admitted to a residential rehabilitation facility and receiving additional services from a plastic surgeon.

3.2 PFC members received follow-up testing to check for remaining cancer cells and possible reoccurrences.

- All PFC members reported having follow-up visits with their surgeon at regular intervals post-surgery, (e.g. one week post-surgery, six months post-surgery, and annually for up to five years).
- Members who received services from other cancer care providers, including radiologists reported also having follow-up with those providers post-treatment.
- Most PFC members reported being very involved in their post-surgical care.

4. PFC Feedback: Value and Quality

4.1 Good communication and coordination were seen as indicators of high quality care.

- PFC members reported being most satisfied with the care they received when they felt they had good communication with their care providers.
- Members also stressed the importance of coordination between providers to ensure quality. One member suggested the lack of coordination between the surgical oncologist and plastic surgeon resulted in avoidable complications.

4.2 Clinicians taking the time to communicate increases quality and value.

- PFC members did not consider the costs of care when deciding on a treatment and care plan; they were solely focused on becoming cancer-free.
- Communication between the clinicians and the PFC members was reported as a mark of high quality and value. Members felt that the care they received overall was excellent or very good, with the exceptions being instances when access to clinicians, information, and clear communication were lacking.

Non-Emergent Coronary Artery Bypass Graft (CABG)

For this measure, five PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 Use of health care services varied greatly during the pre-trigger period.

- PFC members reported different experiences leading up to the diagnosis of arterial blockage. Some PFC members experienced sudden onset of symptoms, such as pain in the chest, arm, or jaw, and they sought care right away while other members were referred for additional cardiovascular testing during routine, outpatient care.
- Based on symptoms, some PFC members reported being scheduled for very near-term surgery, while other PFC members were at home and received outpatient care during the pre-trigger window.

1.2 All PFC members received routine cardiovascular care at the start of the pre-trigger period.

- All PFC members reported receiving cardiovascular care, such as medications or routine stress tests, from a primary care provider or cardiologist prior to surgery.
- During the 30-day pre-trigger period, most PFC members reported having some difficulty doing “usual things” like bathing, dressing, or visiting a doctor’s office at the onset of symptoms. This finding was consistent across those PFC members who did and did not seek care right away for their symptoms.

2. PFC Feedback: Non-Emergent Surgery

2.1 Most PFC members reported working with their cardiologist or surgeon to decide when to have surgery.

- Most PFC members reported talking to their cardiologist or surgeon about their cardiovascular health (e.g., percent blockage in arteries) and the risks and benefits of surgery. A few PFC members also reported discussing alternative treatment options, such as stents.
- Most PFC members reported that it was important to have surgery soon after diagnosis because they were concerned that risk of death was high if they did not have surgery.
- A few PFC members sought a second opinion from an additional cardiologist prior to having surgery.

2.2 The cardiothoracic surgeon and related team led care delivery in the hospital, though other providers were involved.

- All PFC members reported receiving care from a cardiothoracic surgeon, and many also reported receiving substantial services from other members of the health care team including a cardiologist and/or vascular surgeon. If co-occurring conditions existed, members also reported that relevant specialists were involved in preparation for and performance of the surgery.

2.3 Imaging scans and cardiovascular tests were conducted in preparation for surgery.

- Many PFC members noted that the care team ordered imaging scans of their arteries, cardiovascular stress tests, and blood tests in advance of the surgery. For some, these tests were conducted at outpatient facilities, and for others, the testing was done in the hospital.

2.4 Discharge planning was seen as a critical step to recovery and avoiding future complications, including risks of infection and blood clots.

- Many PFC members reported working with the surgeon or a nurse about wound care, medications, and ways to avoid or identify a complication, such as a surgical site infection or blood clot.
- Most PFC members reported that the health care team had an excellent understanding of their personal situation, which led to appropriate post-discharge care either in a rehabilitation facility or at home with support from family and friends or home health aides. Members who reported that their health care team could have had a better understanding of their personal situation thought the surgical team could have improved their coordination with specialists treating co-occurring conditions when considering discharge planning.

3. PFC Feedback: Post-Trigger Window and Services

3.1 Most PFC members received cardiac rehabilitation services and outpatient follow-up visits with their surgeon and cardiologist.

- PFC members reported receiving cardiac rehabilitation in outpatient facilities, rehabilitation facilities, or at home with a home health aide.

- PFC members received a few (two – four) follow-up visits with the surgeon and ongoing care from the outpatient cardiologist during the post-trigger period.

4. PFC Feedback: Value and Quality

4.1 Most PFC members reported that they were satisfied with the quality of care that they received.

- Most PFC members reported receiving excellent quality of care throughout the episode and noted good communication and coordination between the surgeon, the hospital team, and outpatient providers.
- Most PFC members reported that their recovery met their expectations and that their providers accurately described and prepared them for the recovery process.

4.2 Many PFC members did not consider the cost or value of the care they received because information on how to assess value and cost was not available to them.

- Many PFC members reported that they were not certain they would know if care was complete or of “high value” and felt they needed to trust the clinician to provide the right care at the right time.
- Many PFC members reported that they did not consider the costs of care because their surgery was covered by insurance.

Psychoses/Related Conditions

For this measure, four PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 PFC members reported that hospitalization for psychosis and related conditions had no pre-trigger window.

- Half of the PFC members had pre-existing mental health concerns. These PFC members were seeing therapists/counselors and/or psychiatrists and were being treated with medication prior to hospitalization, but reached a point where outpatient services were inadequate to manage their mental health.
- For most PFC members the need for hospitalization came on suddenly; either following a suicide attempt or due to side effects from medication.
- Most PFC members reported being able to do “usual things” like bathing, dressing, or visiting a doctor’s office up until the need for hospitalization, at which time they described having a lot of difficulty with “usual things.”

2. PFC Feedback: Hospitalization

2.1 Initial services at the hospital were frequently delivered to PFC members that were not in a state to make decisions for themselves.

- Most PFC members reported not being lucid during admission to the hospital. A healthcare provider made decisions without the PFC member’s input in these instances. Half of the PFC members suggested the decisions that were made did not improve their condition or overall health.
- One PFC member was able to admit himself and recognized that hospitalization was the only way to stabilize himself.

2.2 Emergency department clinicians, psychiatrists and therapists oversaw health care delivery during hospitalization.

- Most PFC members were initially seen by health care providers in an emergency room or intensive care unit (ICU) before being transferred to a psychiatric ward.
- Most members also reported that there was limited coordination between staff in the emergency setting and the psychiatric ward.
- All PFC members were hospitalized in a psychiatric ward or facility with hospital staff led by a psychiatrist.
- PFC members frequently reported that their primary care physicians and family were not initially contacted or consulted about treatments and medication. The PFC members thought that greater coordination with primary care physicians and family members would have improved their treatment and outcomes.

2.3 Most PFC members did not recall any tests being done prior to, or during hospitalization.

- Most PFC members did not recall any tests being done prior to hospitalization, however one assumed that blood work may have been done.
- One PFC member said her brain function was tested while she was in the ICU to assess possible damage due to a medication overdose.

2.4 Health care goals did not appear to be considered.

- All PFC members that required urgent care during hospitalization reported that they were either not given an opportunity to voice their concerns about their treatment and goals, or that their concerns were dismissed.
- Half of PFC members were given care they felt they did not consent to and/or worsened their condition such as being placed in a co-ed setting or being given electroconvulsive therapy.

2.5 Little was reported in the way of discharge planning after psychosis hospitalization.

- All PFC members reported being discharged without there being a plan in place for health care follow-up.
- PFC members felt solely responsible for their care after discharge.
- All but one PFC member required further care and experienced a subsequent hospitalization at a later time. The one PFC member who did not experience a successive hospitalization discontinued a medication that she believed to be responsible for the onset of the episode, though she had been discharged from the hospital without a medication change from the attending psychiatrist.

3. PFC Feedback: Post-Hospitalization Services

3.1 Follow-up care was only provided after subsequent hospitalizations and typically involved a social worker and/or an outpatient psychiatrist.

- For most PFC members, there was no follow-up with hospital staff after the first hospitalization. Follow-up care only took place after at least one subsequent hospitalization.
- Most PFC members did not think any health care professional was responsible for their care after hospital discharge.
- Follow-up treatment for the triggering event sometimes did not begin until months after the initial hospitalization.
- After subsequent hospitalizations social workers and therapists sometimes became involved to provide health care delivery.

3.2 Psychiatrists or other licensed mental health professionals eventually became involved in care delivery.

- All PFC members eventually received care from a psychiatrist or other mental health professional after the initial hospitalization, as well as care from a primary care physician.
- Half of the PFC members said the psychiatrist or other mental health professional worked in conjunction with their primary care physician.
- One PFC member saw a nurse practitioner for care since it was less expensive than regularly seeing a psychiatrist—though he still had a psychiatrist who was prescribing his needed medications.
- One PFC member described seeing a psychiatrist once a month. She requested that the psychiatrist work in conjunction with a social worker, but the psychiatrist was not interested in collaborative care.

4. PFC Feedback: Value and Quality

4.1 PFC members labeled the care they received as average for mental health episodes, but described care that significantly lacked quality.

- PFC members described hospital staff that did not listen to them and did not communicate with other health care providers or the member's family. PFC members were frequently given low-quality care in which patient history was ignored.
- Most members described being discharged from the hospital without a plan in place for recovery. PFC members often reported being suicidal, unable to care for themselves, and without support or follow-up plans at the time of discharge (i.e., when their involuntary hold times or covered number of days ended). This often resulted in the need for re-hospitalization.
- Members described health care providers releasing them without identifying the trigger for the episode. Some members felt that hospital-based clinicians altered their treatment or medication too rapidly.
- Half of the PFC members described hospital and psychiatrist caseloads that were too large to allow for what they thought was adequate access to the care they needed.

4.2 Clinicians taking the time to communicate and develop a comprehensive treatment plan increases quality and value.

- Most PFC members only thought about their out of pocket costs and not costs to the Medicare program.
- Communication improvements would have significantly increased perceived quality and value of care.
- PFC members reported that it seemed as if clinicians were more focused on discharging patients according to a schedule than they were on addressing the source of the hospitalization.

Renal or Ureteral Stone Surgical Treatment

For this measure, six PFC members were interviewed for the September – October 2018 round of PFC input. This section provides the findings from these interviews.

1. PFC Feedback: Pre-Trigger Window and Services

1.1 The nature of the pre-trigger window varied greatly depending on the severity and urgency of patient symptoms.

- Many PFC members sought treatment for kidney stones through emergency departments, and reported that they first experienced symptoms a few days to a few weeks prior to surgery.
- Some PFC members sought treatment for kidney stones that were detected (due to regular testing for underlying medical conditions) prior to the onset of severe symptoms. These members reported first experiencing symptoms (if at all) a few months or more prior to surgery.
- Several members went to the emergency department on multiple occasions, due to intense pain before ultimately being treated surgically.

2. PFC Feedback: Trigger Event

2.1 Initial services at the hospital were focused on alleviating pain.

- PFC members who were admitted to the hospital as a result of intense pain reported that they would have “done anything” to alleviate their symptoms, and therefore relied primarily on clinician recommendations.
- Almost all members, regardless of the severity of their symptoms, reported that they believed that surgery was “necessary” based on the advice of their clinicians.
- One member reported that she was at risk for kidney stones, but her clinician did not test for them frequently enough, resulting in the need for an emergency surgery.

2.2 Urologists and related specialists led the care team, though other specialists and PCPs were involved in the decision-making process.

- Most PFC members saw a urologist either in advance of the episode trigger or during hospitalization; more than half of members identified a urologist as the health care provider that they thought was primarily responsible for the episode as a whole.
- Some PFC members reported that their urologist or surgeon consulted with their primary care provider or other clinicians that were familiar with their episode.
- Some members were initially seen by a physician in the emergency room. One member reported regularly interacting with the same physician during multiple visits to the emergency department.

2.3 Bloodwork and imaging tests were conducted repeatedly prior to surgery.

- All PFC members reported receiving imaging, and some members reported that they provided blood or urine samples for testing.
- Some of the imaging tests were done on multiple occasions, and members generally reported that this was done to track the location or movement of the stones over time.

2.4 Health care goals included “alleviating pain,” and preventing reoccurrence of stones.

- PFC members reported experiencing excruciating pain as a result of their stones. One noted he was in so much pain that he would have done anything his doctors told him to do in order to make the pain stop.
- Some members reported that other medical conditions (e.g. a preceding kidney transplant) necessitated that any kidney stones be removed, and that their goal was to preserve their long-term health.

2.5 Discharge planning varied, but was typically conducted by an urologist or PCP.

- All members went home following surgery, though the length of stay in the hospital varied between members; some left without spending the night, while others spent two to three nights in the hospital.
- Some members reported receiving minimal discharge recommendations and felt that improved discharge orders could have helped to prevent future stones.

3. PFC Feedback: Post-Hospital Care

3.1 Follow-up care was provided by an urologist, PCP, or other specialist soon after discharge.

- Most PFC members reported receiving follow-up care from an urologist within a month of surgery. Some members then received follow-up care from a primary care provider every three to six months for several years.
- The clinician who managed follow-up care varied from member to member, though it was generally the urologist, primary care provider, or specialist that each member had seen prior to surgery.

4. PFC Feedback: Value and Quality

4.1 Some PFC members reported that the quality of care they received could have been improved.

- Clinicians' communication with patients and coordination between clinicians were the most commonly noted areas for improvement in quality of care received.
- Some members pointed to bedside manner and the amount of time that a clinician was willing to spend with a patient as indicators of quality. Others thought that redundant questions and tests would help them to identify poor-quality care.
- Some PFC members expressed a desire for their clinicians to be more proactive in addressing the causes of their kidney stones, as opposed to waiting for symptoms to appear.

4.2 Members did not report being concerned about cost, and primarily focused on the perceived success of their procedure as an indicator of value.

- No PFC member reported being concerned by the costs associated with their treatment. Some were covered exclusively by Medicare, and others had supplemental insurance, but they all reported being primarily focused on getting well.
- Overall, members reported receiving high-value care, though they often described care that involved multiple consecutive visits to the emergency department, and did not involve comprehensive discharge planning or patient-provider communication.