

## Perinatal Quality Collaborative of North Carolina



**Overall Aim:** Create and strengthen a multidisciplinary hospital based community focused on providing a standardized approach to diagnosis and management of patients with hypertension in pregnancy with no increase in maternal ICU admission and a reduction in NICU admissions while implementing the six steps of Patient Family Centered Care Methodology / Practice to improve the care experience of preeclampsia patients and their families by 30-September 2017.

| Secondary Aim              | Primary Drivers  | Secondary Drivers   |
|----------------------------|--|---|
| <b>1 Proper Diagnosis</b>  | <p>1.1 Accurate measurement of blood pressure in all patients diagnosed with preeclampsia</p> <p>1.2 Proper definition of hypertensive disorders</p> <p>1.3 Early ID of severe features</p>  | <p>1.1.1 Proper placement, proper cuff size</p> <p>1.1.2 Each L&amp;D develops appropriate education to ensure staff competency</p> <p>1.1.3 Annual competency assessment</p> <p>1.2.1 Use and Incorporate ACOG Position paper into hospital policy for defining hypertensive disorders of pregnancy (5 ACOG Diagnoses) (see CMOP Action Plan Appendix)</p> <p>1.2.2 Each L&amp;D develops appropriate education to ensure staff competency</p> <p>1.3.1 Adoption of preeclampsia early recognition tool (PERT) or equivalent tool (see CMOP Action Plan Appendix)</p> <p>1.3.2 Each L&amp;D develops appropriate education to ensure staff competency and family understanding (e.g., use of the Preeclampsia Foundation Signs and Symptoms Information Sheet and ACOG Key Components of Effective Health Communication and Patient Education(see CMOP Action Plan Appendix)</p> |
| <b>2 Proper Management</b> | <p>2.1 Treatment or control of severe range blood pressures within 60 minutes.</p> <p>2.2 Provision of a full course of ANS for eligible pregnancies less than 34 weeks</p> <p>2.3 Reduce deliveries of women prior to 37 weeks solely for gestational hypertension and preeclampsia without severe features (conservative obstetric management)</p> | <p>2.1.1 Develop systems to immediately communicate confirmed severe range blood pressures to appropriate provider</p> <p>2.1.2 Develop guidelines to assure control severe range (with or without medications)</p> <p>2.1.3 Each L&amp;D develops appropriate education to ensure staff competency</p> <p>2.2.1 Develop guidelines for proper and timely administration</p> <p>2.2.2 Develop guidelines for eligibility</p> <p>2.2.3 Each L&amp;D develops appropriate education to ensure staff competency</p> <p>2.3.1 Develop protocols to safely delay delivery after 37 weeks for women with gestational hypertension and preeclampsia without severe features</p> <p>2.3.2 Develop guidelines for eligibility for delivery after 37 weeks for women with gestational hypertension and preeclampsia without severe features</p>   |

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|                                    |   |   |
|------------------------------------|---|---|
| <b>2 Proper Management (cont.)</b> | 2.4 Magnesium administered to appropriate mothers   | 2.3. 3 Each L&D develops appropriate education to ensure staff competency<br><br>2.4.1 Develop guidelines for proper and timely administration<br>2.4.2 Develop guidelines for eligibility<br>2.4.3 Each L&D develops appropriate education to ensure staff competency  |
| <b>3 Proper Discharge</b>          | 3.1 Implementation of CMQCC discharge regimen including patient education handouts (see CMOP Action Plan Appendix)<br><br>3.2 Ensure proper postpartum BP monitoring<br><br>3.3 Ensure proper postpartum education<br><br>3.4 Ensure timely and appropriate discharge from the hospital | 3.1.1 Use of CMQCC Sample Discharge Instructions Following Delivery with Diagnosed Preeclampsia or equivalent<br>3.1.2 Use of CMQCC Sample Discharge Sheet for Preeclampsia, Eclampsia and HELLP Syndrome Patients or equivalent<br>3.1.3 Use of ACOG Key Components of Effective Health Communication and Patient Education or equivalent<br>3.1.4 Each L&D develops appropriate education to ensure staff competency<br><br>3.2.1 Develop system to ensure that BP is measured at 72 hours post-delivery<br>3.2.2 Develop system to ensure appropriate follow-up BP measurement 7-10 days postpartum<br>3.2.3 Each L&D develops appropriate education to ensure staff competency<br><br>3.3.1 Use of ACOG Key Components of Effective Health Communication and Patient Education or equivalent<br>3.3.2 Advise patient about future implications of preeclampsia<br>3.3.3 Advise of lifetime risk for cardiovascular disease<br>3.3.4 Advise of what needs to happen at postpartum visit<br>3.3.5 Each L&D develops appropriate education to ensure staff competency<br><br>3.4.1 Develop local standards of care and management of postpartum patients with hypertension in pregnancy<br>3.4.2 Develop relationships with ancillary services that may allow earlier discharge in appropriate patients<br>3.4.3 Use length of stay data to assess change in inpatient stays |

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|   |   |   |
|---|---|---|
| <b>3 Proper Discharge (cont)</b>  | 3.5 Identifying postpartum complications  | 3.5.1 Engage and educate non-OB providers to identify patients with potential post-partum complications of preeclampsia<br>3.5.2. Develop protocols and communication systems to identify women with potential postpartum complications seen outside the OB unit (ER, ICU, etc) |
| <b>4 Each PQIT will identify team members who will lead the efforts to engage patients and families</b> | 4.1 Determine if other departments/teams should be engaged; for example, hospitals that have previously participated in PQCNC PFE initiatives may want to partner with the individuals who led that work<br><br>4.2 Identify the characteristics/skills necessary to lead PFE efforts within your PQIT<br><br>4.3 Define the role and responsibilities for the PQIT PFE Lead, including a plan for communicating with patients/families, and other team members<br><br>4.4 Identify potential candidates through a referral and self-nomination process |   |
| <b>5 Each PQIT will incorporate patients / family members directly into the team</b>                    | 5.1 Develop communication strategies that effectively target the patient/family population for CMOP<br><br>5.2 Develop processes to identify/recruit patients and families with experiences centered on preeclampsia as team members on PQITs<br><br>5.3 Develop patient, family and staff education materials, including creation of a web-based video, highlighting importance of patient/family voice/experience   |   |

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|   |  |   |
|---|--|---|
| <p><b>6 Each PQIT will select a care experience related to preeclampsia to transform with patients and their families</b></p>             | <p>6.1 Identify potential care experiences related to preeclampsia to focus on (e.g., diagnosis, management, treatment, postpartum care); Note: PQIT's may choose to address the entire care experience of preeclampsia patients and their families, or, they may start by selecting a more narrowly focused care experience, such as "discharge education"</p> <p>6.2 Select a care experience using guidance from providers, staff, and existing patient/family feedback</p> <p>6.3 Define the beginning/end points of the care experience on which you have chosen to focus</p> |   |
| <p><b>7 Each PQIT will evaluate the current state of the selected care experience through the eyes of patients and their families</b></p> | <p>7.1 Develop a care experience flow map</p> <p>7.2 Collect stories of the care experience</p>  | <p>7.1.1 Identify team members to shadow patients and families, documenting direct, real-time observations of patients and families as they move through each step of the selected care experience; consider including individuals who are able to shadow at a variety of care times (e.g., days, nights, weekends)</p> <p>7.1.2 Create a form for the shadower to document the following: where patients and families go during the selected care experience, individuals the patient/family comes in contact with, steps in the care process and how long each step takes, patient/family reactions at each step</p> <p>7.2.1 Determine perspective/experience desired in potential patient and family partners sharing stories</p> <p>7.2.2 Identify sources to approach for patient/family member referrals</p> <p>7.2.3 Identify a person(s) on the PQIT be the point of contact for patient/family members, to prepare them regarding logistics, questions to be asked, etc.</p> <p>7.2.4 Invite patients and families to share their care experiences with the PQIT through the sharing of written stories, videos, or inviting patients/families to speak at meetings</p> |

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|  |   |  |
|--|---|--|
| <b>7 Each PQIT will evaluate the current state of the selected care experience through the eyes of patients and their families (cont)</b>                  | <p>7.3 Collect survey data of the care experience</p>   | <p>7.3.1 Develop and administer a short, simple, focused survey for patients and families to complete regarding the selected care experience<br/>7.3.2 Gather results from existing reports, such as patient satisfaction data<br/>7.3.4 Develop a process for sharing the results from the patient/family surveys</p>   |
| <b>8 Each PQIT will establish a working group which will develop specific patient and family engagement processes to incorporate into ideal care story</b> | <p>8.1 Select the PQIT PFE Lead as the working group leader</p> <p>8.2 Use the care experience flow map to identify working group members</p> <p>8.3 Plan and schedule the kick-off meeting, followed by weekly, bi-weekly meetings</p> | <p>8.2.1 Determine which departments the patient/family member comes in contact with during the selected care experience; this may include physicians, nurses, aides, those who work in the operating room, therapists, social service providers, dieticians, unit secretaries, pharmacists, or others<br/>8.2.2 Define the role and responsibilities for work group members, including time requirements<br/>8.2.3 Identify potential candidates through a referral and self-nomination process</p> <p>8.3.1 Consider providing an invitation or welcome letter to work group members signed by a member of senior leadership<br/>8.3.2 Prepare background materials to review at the kick-off meeting; this may include survey data or stories collected from patients and families, as well as a copy of the care experience flow map<br/>8.3.3 Ask senior leaders to attend the kick-off meeting to establish their support for the work<br/>8.3.4 Ensure that future meeting dates are established prior to the end of the kick-off meeting</p> |
| <b>9 Each PQIT will create a shared vision by writing the ideal care story from patient/family viewpoints</b>  | <p>9.1 Ask every member of the working group to imagine themselves as a patient/family member and write down their ideal experience in the form of a story, for the selected care experience</p>  | <p>9.1.1 Consider each touchpoint and caregiver that patients and family members come in contact with throughout the selected care experience, as well as each process they go through along the way<br/>9.1.2 Determine what the ideal care experience should look like and feel like, every step of the way</p>  |

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|   |  |   |
|---|--|---|
| <b>9 Each PQIT will create a shared vision by writing the ideal care story from patient/family viewpoints (cont)</b>  | <p>9.2 Discuss and share individual stories</p> <p>9.3 Create a collective story that will become the shared vision of the working</p>   |   |
| <b>10 Each PQIT will work to close the gaps between the current state care experiences and the ideal, closely tracking each hospital's work and it's impact</b> | <p>10.1 Identify potential projects by comparing the current state to the ideal patient and family care experience, as prioritized by patients and families</p> <p>10.2 Identify individuals within the working group to lead a project(s); additional team members from within the working group, PQIT, or outside of those groups may join the project team</p> <p>10.3 Project teams will develop, test, implement, and evaluate the results of projects</p> <p>10.4 Project team co-leads report on the status of projects at working group and/or PQIT meetings</p> | <p>10.1.1 Review the feedback collected from patients and families (through surveys, storytelling, care experience flow map, etc.) and look for recurring themes</p> <p>10.1.2 Make and maintain a list of care experience improvement ideas</p> <p>10.3.1 Focus on easy-to-do, low-tech solutions to start</p> |

# CMOP Action Plan

**CMOP Action Plan Appendix follows providing resources referred to in the Action Plan and the *PFCC Go Guide* featuring the *The Patient and Family Centered Care Methodology and Practice - The New Operating System for Healthcare***

## Classification of Hypertensive Disorders

The major goals of a hypertension classification schema, which describes hypertension that complicates pregnancy, are to differentiate diseases preceding conception from those specific to pregnancy, identify the most ominous causes, and create categories ideal for record keeping and eventual epidemiologic research. Nevertheless, health care professionals continue to be confused by the differences in terminology that abound in the literature, especially the differences in publications from national and international societies. These latter reports continue to introduce schema that differ in various documents and may contrast with those recommended here. This confusion has obviously affected both management and outcome research and recommendations.

The American College of Obstetricians and Gynecologists (the College) Task Force on Hypertension in Pregnancy chose to continue using the classification schema first introduced in 1972 by the College and modified in the 1990 and 2000 reports of the National High Blood Pressure Education Program Working Group (1). Similar classifications can be found in the American Society of Hypertension guidelines, as well as College Practice Bulletins (2, 3). Although the task force has modified some of the components of the classification, it continues with this basic, precise, and practical classification, which considers hypertension during pregnancy in only four categories:

1) preeclampsia–eclampsia, 2) chronic hypertension (of any cause), 3) chronic hypertension with superimposed preeclampsia; and 4) gestational hypertension.

It has been suggested that an older category, “unclassified,” be reintroduced or replaced by “suspected” or “presumptive” preeclampsia. This may be useful in management because one should always be prepared for the disorder with the greatest risk. However, although these latter terms may help guide clinical practice, they may hinder record keeping for precise epidemiological research.

### Preeclampsia–Eclampsia

Preeclampsia is a pregnancy-specific hypertensive disease with multisystem involvement. It usually occurs after 20 weeks of gestation, most often near term, and can be superimposed on another hypertensive disorder. *Preeclampsia*, the most common form of high blood pressure (BP) that complicates pregnancy, is primarily defined by the occurrence of new-onset hypertension plus new-onset proteinuria. However, although these two criteria are considered the classic definition of preeclampsia, some women present with hypertension and multisystemic signs usually indicative of disease severity in the absence of proteinuria. In the absence of proteinuria, preeclampsia is diagnosed as hypertension in association with thrombocytopenia (platelet count less than 100,000/microliter), impaired



liver function (elevated blood levels of liver transaminases to twice the normal concentration), the new development of renal insufficiency (elevated serum creatinine greater than 1.1 mg/dL or a doubling of serum creatinine in the absence of other renal disease), pulmonary edema, or new-onset cerebral or visual disturbances.

*Hypertension* is defined as either a systolic BP of 140 mm Hg or greater, a diastolic BP of 90 mm Hg or greater, or both. Hypertension is considered mild until diastolic or systolic levels reach or exceed 110 mm Hg and 160 mm Hg, respectively. It is recommended that a diagnosis of hypertension require at least two determinations at least 4 hours apart, although on occasion, especially when faced with severe hypertension, the diagnosis can be confirmed within a shorter interval (even minutes) to facilitate timely antihypertensive therapy.

Proteinuria is diagnosed when 24-hour excretion equals or exceeds 300 mg in 24 hours or the ratio of measured protein to creatinine in a single voided urine measures or exceeds 3.0 (each measured as mg/dL), termed the protein/creatinine ratio. As discussed in Chapter 2 “[Establishing the Diagnosis of Preeclampsia and Eclampsia](#),” qualitative dipstick readings of 1+ suggest proteinuria but have many false-positive and false-negative results and should be reserved for use when quantitative methods are not available or rapid decisions are required.

Eclampsia is the convulsive phase of the disorder and is among the more severe manifestations of the disease. It is often preceded by premonitory events, such as severe headaches and hyperreflexia, but it can occur in the absence of warning signs or symptoms.

Specific biochemical markers have been linked to increased morbidity in hypertensive complications of pregnancy (eg, hyperuricemia), but these should not be used for diagnosis. Although some label preeclampsia as “less severe” or “more severe”, or “mild” and “severe,” these are not specific classifications, and the consideration of preeclampsia as “mild” should be avoided. The task force recommends that the term “mild preeclampsia” be replaced by “preeclampsia without severe features.” These points are more extensively discussed in Chapter 2 “[Establishing the Diagnosis of Preeclampsia and Eclampsia](#).”

## Chronic Hypertension

During pregnancy, *chronic hypertension* is defined as high BP known to predate conception or detected before 20 weeks of gestation. Previously, some suggested that when high BP is first diagnosed in the first

half of pregnancy and normalizes postpartum, the diagnosis should be changed to “transient hypertension of pregnancy.” However, because discharge records are rarely modified, the task force recommends against instituting this latter terminology.

## Chronic Hypertension With Superimposed Preeclampsia

Preeclampsia may complicate all other hypertensive disorders, and in fact the incidence is four to five times that in nonhypertensive pregnant women (4). In such cases, prognosis for the woman and her fetus is worse than either condition alone. Although evidence from renal biopsy studies suggests that the diagnosis of superimposed preeclampsia may be often erroneous (5), the diagnosis is more likely in the following seven scenarios: women with hypertension only in early gestation who develop proteinuria after 20 weeks of gestation and women with proteinuria before 20 weeks of gestation who 1) experience a sudden exacerbation of hypertension, or a need to escalate the antihypertensive drug dose especially when previously well controlled with these medications; 2) suddenly manifest other signs and symptoms, such as an increase in liver enzymes to abnormal levels; 3) present with a decrement in their platelet levels to below 100,000/microliter; 4) manifest symptoms such as right upper quadrant pain and severe headaches; 5) develop pulmonary congestion or edema; 6) develop renal insufficiency (creatinine level doubling or increasing to or above 1.1 mg/dL in women without other renal disease); and 7) have sudden, substantial, and sustained increases in protein excretion.

If the only manifestation is elevation in BP to levels less than 160 mm Hg systolic and 110 mm Hg diastolic and proteinuria, this is considered to be superimposed preeclampsia without severe features. The presence of organ dysfunction is considered to be superimposed preeclampsia with severe features. For classification purposes, both variants are termed “superimposed preeclampsia,” but management is guided by the subcategory (analogous to “preeclampsia with severe features” and “preeclampsia without severe features”).

## Gestational Hypertension

Gestational hypertension is characterized most often by new-onset elevations of BP after 20 weeks of gestation, often near term, in the absence of accompanying proteinuria. The failure of BP to normalize postpartum requires changing the diagnosis to chronic hypertension.



Outcomes in women with gestational hypertension usually are quite successful, although some of these women experience BP elevations to the severe level with outcomes similar to women with preeclampsia (6). The cause of this entity is unclear, but many of these women have preeclampsia before proteinuria and other organ manifestations have occurred. Thus, gestational hypertension, even when BP elevations are mild, requires enhanced surveillance.

Gestational hypertension, although transient in nature, may also be a sign of future chronic hypertension. Thus, even when benign, it is an important marker regarding follow-up and preventive medicine decisions (7).

### Postpartum Hypertension

It is important to remember that preeclampsia—including preeclampsia with severe systemic organ involvement and seizures—can first develop in the postpartum period. Because early hospital discharge is the current practice in the United States, this mandates instruction of women at discharge from the hospital to be aware of symptoms (eg, severe headache, visual disturbances, or epigastric pain) that should be reported to a health care provider.

Although not recommended in this classification schema, the task force calls attention to a phenomenon once labeled “late postpartum hypertension,” a disorder that was more frequently diagnosed when women in the postpartum period routinely remained hospitalized for as long as 2 weeks. It was defined as women with normotensive gestations who develop

hypertension (usually mild) in a period that ranges from 2 weeks to 6 months postpartum. Blood pressure remains labile for months postpartum, usually normalizing by the end of the first year. Little is known of this entity, and, like gestational hypertension, it may be a predictor of future chronic hypertension.

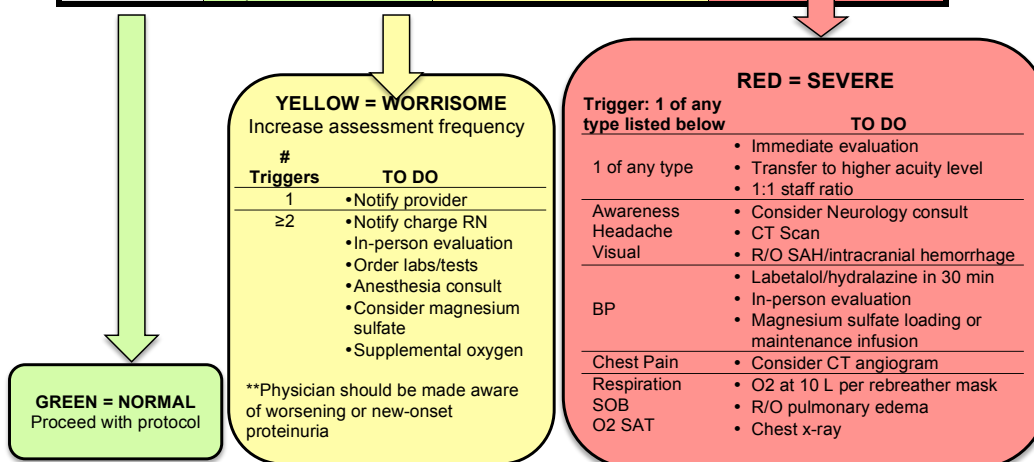
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6. Buchbinder A, Sibai BM, Caritis S, Macpherson C, Hauth J, Lindheimer MD, et al. Adverse perinatal outcomes are significantly higher in severe gestational hypertension than in mild preeclampsia. National Institute of Child Health and Human Development Network of Maternal-Fetal Medicine Units. *Am J Obstet Gynecol* 2002;186:66–71. [\[PubMed\]](#) [\[Full Text\]](#) ↩
7. Williams D. Long-term complications of preeclampsia. *Semin Nephrol* 2011;31:111–22. [\[PubMed\]](#) ↩

## Appendix D: Preeclampsia Early Recognition Tool (PERT)

Preeclampsia Early Recognition Tool (PERT)

| ASSESS   | NORMAL (GREEN)  | WORRISOME (YELLOW)  | SEVERE (RED)  |
|--|---|---|---|
| <b>Awareness</b>   | Alert/oriented  | <ul style="list-style-type: none"> <li>•Agitated/confused</li> <li>•Drowsy</li> <li>•Difficulty speaking</li> </ul> | <ul style="list-style-type: none"> <li>•Unresponsive</li> </ul>   |
| <b>Headache</b>  | None  | <ul style="list-style-type: none"> <li>•Mild headache</li> <li>•Nausea, vomiting</li> </ul>                         | <ul style="list-style-type: none"> <li>•Unrelieved headache</li> </ul>  |
| <b>Vision</b>  | None  | <ul style="list-style-type: none"> <li>•Blurred or impaired</li> </ul>  | <ul style="list-style-type: none"> <li>•Temporary blindness</li> </ul>  |
| <b>Systolic BP (mm HG)</b>   | 100-139   | 140-159   | ≥160  |
| <b>Diastolic BP (mm HG)</b>  | 50-89   | 90-105  | ≥105  |
| <b>HR</b>  | 61-110  | 111-129   | ≥130  |
| <b>Respiration</b>   | 11-24   | 25-30   | <10 or >30  |
| <b>SOB</b>   | Absent  | Present   | Present   |
| <b>O2 Sat (%)</b>  | ≥95   | 91-94   | ≤90   |
| <b>Pain: Abdomen or Chest</b>  | None  | <ul style="list-style-type: none"> <li>•Nausea, vomiting</li> <li>•Chest pain</li> <li>•Abdominal pain</li> </ul>   | <ul style="list-style-type: none"> <li>•Nausea, vomiting</li> <li>•Chest pain</li> <li>•Abdominal pain</li> </ul> |
| <b>Fetal Signs</b>   | <ul style="list-style-type: none"> <li>•Category I</li> <li>•Reactive NST</li> </ul>  | <ul style="list-style-type: none"> <li>•Category II</li> <li>•IUGR</li> <li>•Non-reactive NST</li> </ul>            | <ul style="list-style-type: none"> <li>•Category III</li> </ul>   |
| <b>Urine Output (ml/hr)</b>  | ≥50   | 30-49   | ≤30 (in 2 hrs)  |
| <b>Proteinuria</b><br>(Level of proteinuria is not an accurate predictor of pregnancy outcome) | Trace   | <ul style="list-style-type: none"> <li>•&gt; +1**</li> <li>•≥300mg/24 hours</li> </ul>                              |   |
| <b>Platelets</b>   | >100  | 50-100  | <50   |
| <b>AST/ALT</b>   | <70   | >70   | >70   |
| <b>Creatinine</b>  | <0.8  | 0.9-1.1   | ≥1.2  |
| <b>Magnesium Sulfate Toxicity</b>  | <ul style="list-style-type: none"> <li>•DTR +1</li> <li>•Respiration 16-20</li> </ul> | <ul style="list-style-type: none"> <li>•Depression of patellar reflexes</li> </ul>                                  | <ul style="list-style-type: none"> <li>•Respiration &lt;12</li> </ul>   |



## Patient Education: Appendices O-Q

### Appendix O: Preeclampsia Foundation Signs and Symptoms Information Sheet

**Ask Your Doctor or Midwife**

# Preeclampsia

**What Is It?**

Preeclampsia is a serious disease related to high blood pressure. It can happen to any pregnant woman.

**Risks to You**

- Seizures
- Stroke
- Organ damage
- Death


**Risks to Your Baby**

- Premature birth
- Death

**Signs of Preeclampsia**




Stomach pain




Headaches




Feeling nauseous; throwing up



Seeing spots



Swelling in your hands and face



Gaining more than 5 pounds in a week

**What Should You Do?**

Call your doctor right away. Finding preeclampsia early is important for you and your baby.

**For more information go to [www.preeclampsia.org](http://www.preeclampsia.org)**

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To order materials, go to: [www.preeclampsia.org/market-place](http://www.preeclampsia.org/market-place)

## Patient Education

Many millions of dollars have been spent on clinical and laboratory research in an effort to discover the pathogenesis of prophylactic measures for and optimal treatment of preeclampsia. Although these goals are of the utmost importance, a more effective use of currently available information and resources may reduce the burden of morbidity and mortality that arises in association with preeclampsia. Health services interventions, including patient education, may not only help to reduce this burden, particularly among populations at greatest risk (eg, those with low health literacy or at highest risk of developing preeclampsia), but also may reach that goal at a relatively low cost. Patient and health care provider education is key to the successful recognition and management of preeclampsia. Health care providers need to inform women during the prenatal and postpartum periods of the signs and symptoms of preeclampsia and stress the importance of contacting health care providers if these are evident. This can be accomplished without increasing patient anxiety (1).

Little is understood about how to best educate women about preeclampsia and provide them with the information needed to seek prompt and appropriate care. What is known is that the population, in general, has difficulty understanding even basic health information, and preeclampsia, specifically, is a poorly understood complication of pregnancy (2). Education techniques that are appropriate for patients with poor

literacy skills have been researched and described in the literature. These can be applied to patient education about preeclampsia with the goal of ensuring that the best possible outcomes are achieved with the resources currently available.

### Importance of Patient Education

In the developed world, the frequency of adverse maternal and perinatal events related to preeclampsia remains markedly lower than in developing countries, largely because of the greater number of available resources and routine hypertension and proteinuria screening (3–5). Interventions for women with disease include increased monitoring, magnesium sulfate, antihypertensive medications, corticosteroids for fetal lung maturation, and delivery. To maximally benefit from these resources, however, women must first seek medical care in a timely fashion.

The possibility that women do not seek timely care may be increased if they have a poor understanding of the signs and symptoms of preeclampsia. Several recent studies emphasized the potential value of educating patients to report and their health care providers to act on signs and symptoms of severe preeclampsia that commonly precede eclampsia, hypertensive encephalopathy, pulmonary edema, or stroke (6–11). This hypothesis is further supported by studies of women in whom preeclampsia was diagnosed, received timely and proper surveillance, and had fewer adverse events

than those with delayed diagnosis (12). Regardless of literacy level and understanding of preeclampsia, this knowledge deficit appears to be modifiable because women who acknowledge receiving information about the disease demonstrate greater preeclampsia-specific knowledge (2).

Beyond improving outcomes, it is the ethical responsibility of the health care system and the health care providers who work within that system to ensure that patients have been educated about the implications and complications of a specific health state, including pregnancy. According to the American Medical Association, “Patients have the right to understand healthcare information that is necessary for them to safely care for themselves, and to choose among available alternatives. Health care providers have a duty to provide information in simple, clear and plain language and to check that the patients have understood the information before ending the conversation” (13).

### Patient Education Strategies

Although few would debate the importance of patient education, the question still remains as to how best to provide such education about preeclampsia. The solution is complex because it is estimated that approximately one half of the American population has a limited capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (14, 15). In addition, an overall paucity of published research addresses patient education in the context of pregnancy. Consequently, models for successful interventions that address health-related outcomes are found outside the context of pregnancy. In 2007, the American Medical Association Foundation published a monograph summarizing research related to health literacy. The publication also provided recommendations on how health care pro-

viders can effect change in the practice environment as it relates to patient education when considering a population with limited health literacy (16). A summary of recommendations is listed in [Box 9-1](#).

Predicting who is affected by inadequate health literacy skills is challenging because the problem is ubiquitous, spanning all races and income and education levels. Certainly, an obstetric care provider can relay both the symptoms of preeclampsia in nonmedical language ([Box 9-1](#)) and the appropriate actions that should be taken should those symptoms arise; however, if that message is relayed in a manner that is poorly understood by the patient, it is of little to no value. Hence, any educational intervention should be created so that patients with even limited literacy skills can understand and act on the information.

It is not only important that medical care providers offer easy-to-understand and straightforward verbal communication, but also that appropriate aids are used for women to take with them that offer visual reminders at home. These should be written at no greater than a fifth-grade or sixth-grade reading level, be graphic-based, and be culturally sensitive (16–21). For example, relaying to a patient that she should notify her health care provider if she experiences right upper quadrant pain, headache, or visual alterations may be confusing to the patient and her family. The health care provider should instead explain that the patient should notify her health care provider if she has pain in her stomach, has a headache, or sees spots. The health care provider could then point to the areas of concern (abdomen, head, and eyes) and provide a graphic-based tool intended to relay the same concept (22, 23). A group of researchers found that after distributing a card depicting pictures of preeclampsia signs and symptoms to women in certain Jamaican parishes, women from these parishes had lower rates of preeclampsia-related morbidity than women from

#### BOX 9-1. Key Components of Effective Health Communication and Patient Education ↵

- Do not assume a patient’s literacy level or understanding based on her appearance.
- In both oral and written communication, use plain, nonmedical language.
- Speak slowly.
- Organize information into two or three components.
- Ask the patient to “teach back” information to confirm understanding.

Data from Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. Health literacy: a prescription to end confusion. Committee on Health Literacy, Board on Neuroscience and Behavioral Health, Institute of Medicine. Washington, D.C.: The National Academies Press; 2004. p. 345.

parishes who had not received the card (22). The health care provider should also ask the patient to “teach back” the information to confirm the patient’s understanding. An example would include, “We have gone over a lot of information. In your own words, can you tell me what we discussed today? What would make you call your health care provider or come to the hospital?” This should take the place of close-ended questions such as, “Did you understand the material discussed today?” (16).

Grouping information together and then checking for understanding—“chunk and check”—also is a way to provide information that is easier to understand and remember. When applying this concept to preeclampsia, a health care provider could break down the conversation by explaining the syndrome, its implications, the associated symptoms, and the appropriate actions that should be used if a patient experiences symptoms. Each of these broad ideas could include two or three details (Box 9-2). The health care provider should check for understanding using the teach-back method before moving on to the next idea (16).

Mobile applications are increasingly being used to reach diverse populations. More than 85% of Americans own a cell phone, and 72% of cell phone users send or receive text messages (24). Text4Baby, a text-messaging program that sends out timed prenatal and postpartum information to registered mobile phones, recently reported positive results since its launch in February 2010 (25). Time spent in the patient reception area can be used to convey information by way of TV monitors and print material written at the

fifth-grade to sixth-grade reading level. Group prenatal care, often called “centering pregnancy,” has been found to be effective in conveying information and improving perinatal outcomes at no added cost (26).

## Patient Education Barriers

There are several barriers that may preclude a health care provider’s ability to educate patients about preeclampsia (Box 9-3). The amount of time available for each prenatal visit is limited, and a great deal of information has to be relayed in a typical prenatal appointment. It is important to note that many of the aforementioned techniques actually require little time. If they are spread out over several visits starting as early as 15 weeks of gestation, but no later than 20 weeks of gestation, and reviewed several times during the course of the pregnancy, it would only take a few minutes to discuss this information. In some settings, health care systems have successfully used a centering pregnancy model, whereby women are grouped together by due dates for prenatal education and support (27–29). Some may believe that providing a patient with information about preeclampsia will produce unnecessary anxiety. There is evidence to the contrary because failure to educate patients about preeclampsia may cause women to experience greater fear because of lack of information (1).

Evidence suggests that health care providers who fail to inform patients about preeclampsia may do so because the health care provider is underinformed. A 2002 survey of obstetrician–gynecologists revealed

### BOX 9-2. Chunk-and-Check ⇐

#### What is it?

Definition of preeclampsia in layman’s terms: “Preeclampsia is a serious disease related to high blood pressure. It can happen to any pregnant woman.”

#### Why should you care?

Explanation of risks to the patient and her infant, emphasizing the seriousness of responding in a timely manner: “There are risks to you: seizures, stroke, organ damage, or death; and to your baby: premature birth or death.”

#### What should you pay attention to?

Explanation of potentially concerning signs and symptoms accompanied by graphics and simply written description: “Symptoms include...”

#### What should you do?

Explanation of appropriate actions that should be taken if a patient experiences symptoms: “If you experience any concerning symptoms, call your health care provider right away. Finding preeclampsia early is important for you and your baby.”

**BOX 9-3. Most Commonly Reported Barriers to Providing Preeclampsia Education** ↩

- Health care providers have too many important issues to address and not enough time.
- Information overload is causing women to be too anxious about their pregnancies.
- Materials that are written simply, available in other languages, and affordable, are not available.
- Health care providers are unsure about what information needs to be provided that will affect outcomes.

great disparities in their knowledge and clinical management of hypertensive disorders of pregnancy (30). Health care providers need to understand that preeclampsia without severe features can progress quickly and unexpectedly; that proteinuria is not always present, even in severe forms of preeclampsia; that women remain at risk of preeclampsia postpartum; and that a woman's symptoms should not be dismissed without a proper assessment. This is corroborated by thousands of patient experiences reported to the Preeclampsia Foundation (31). Many clinicians and patients are unaware that preeclampsia can still occur after delivery. Postpartum hypertension or preeclampsia either is a new-onset condition or is secondary to persistence or exacerbation of hypertension in women with previous gestational hypertension, preeclampsia, or chronic hypertension (32). In cases of late postpartum eclampsia, researchers found that almost all of the patients had at least one prodromal symptom, and one half had more than one symptom that heralded the seizure. However, only 33% of women sought care for their symptoms, suggesting that proper patient education may have led to better outcomes (9).

In addition, it should be recognized that many of the pamphlets developed with the intention of educating women about issues related to obstetrics and gynecology may be written at a higher readability level than that recommended for the general public (33). Therefore, those who provide obstetric care cannot assume that all available patient literature will be effective. The limited number of appropriately written materials available to educate women about preeclampsia is a perceived and underresearched barrier to providing patient education about preeclampsia (23).

When women know how to recognize the signs and symptoms and they understand the information offered, they have the opportunity to report symptoms more promptly, request appropriate investigations and follow-up, reduce their fear and anxiety, and adhere to

prescribed management. This all leads to improved pregnancy outcomes.

**TASK FORCE RECOMMENDATION**

- It is suggested that health care providers convey information about preeclampsia in the context of prenatal care and postpartum care using proven health communication practices.

*Quality of evidence:* Low

*Strength of recommendation:* Qualified

This chapter was developed with the assistance of Whitney You, MD.

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## Appendix P: SAMPLE: Discharge Instructions Following Delivery with Diagnosed Preeclampsia

[NAME OF HOSPITAL, CLINIC OR PRACTICE]  
[PHONE NUMBER]

### DISCHARGE INSTRUCTIONS FOLLOWING DELIVERY OF BABY PREECLAMPSIA

During your hospitalization, you have been treated for preeclampsia or HELLP syndrome. Preeclampsia is a problem that can occur in the late stages of pregnancy and even *during the first few weeks postpartum* (after delivery of your baby), and causes high blood pressure, protein in the urine and sometimes other symptoms such as headaches, blurred vision, breathlessness, and swelling of the hands or face. In the past, it has been called “toxemia” or “pregnancy-induced hypertension”. HELLP syndrome is a variation of preeclampsia that directly affects your liver and blood platelets.

Preeclampsia can be mild or severe. If it isn’t treated, preeclampsia can turn into a serious problem called “eclampsia” in which seizures occur.

#### When you go home, follow these instructions:

- Keep follow-up appointments with your doctor. These may be very frequent and are very important for your health.
- Take all medications prescribed for you exactly as ordered.
- Weigh yourself at the same time each day. Write down your weight and take this record with you to your doctor visits.
- If ordered by your doctor, monitor your blood pressure at home.
- Ask your doctor if you need to check your urine at home for protein.
- Eat a healthy, balanced diet. Your doctor will tell you if you need to follow any special restrictions in what you eat.
- Don’t smoke.
- Don’t drink alcohol or use any drugs not prescribed to you.
- Ask your doctor before taking any medications that he or she didn’t prescribe for you. This includes any over-the-counter medications.

#### Call your doctor if:

- Your blood pressure is greater than \_\_\_\_\_ systolic (the top or first number).
- Your blood pressure is greater than \_\_\_\_\_ diastolic (the bottom or second number).
- You have a severe headache or dizziness.
- You have any headache that is not relieved with Tylenol or ibuprofen (e.g., Advil™, Motrin™).
- You have pain in your belly, especially the right upper area below your ribs.
- You have blurry or double vision, see spots or auras.
- Your swelling is worse.
- You gain more than 3 pounds in 3 days.
- You have serious difficulty catching your breath.
- You have any new or unusual symptoms.
- You have any questions or concerns.

***If you have any of the above symptoms, call [phone number] immediately. If you are unable to reach your physician you need to go to the emergency room for evaluation. Be sure to tell them you just had a baby and you had preeclampsia.***

Additional information about preeclampsia can be found at [www.preeclampsia.org](http://www.preeclampsia.org). There you will find accurate information about preeclampsia and related disorders of pregnancy, as well as a very friendly and helpful community of women with whom you can discuss any concerns or questions.

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## Appendix Q: SAMPLE: Discharge Sheet for Preeclampsia, Eclampsia and HELLP Syndrome Patients

### Discharge Information for Patients with Diagnosis of Preeclampsia, HELLP Syndrome or Eclampsia

Your Medications include the following:

1) \_\_\_\_\_ To be taken every \_\_\_\_ hours.

2) \_\_\_\_\_ To be taken every \_\_\_\_ hours.

3) \_\_\_\_\_ To be taken every \_\_\_\_ hours.

Your postpartum follow-up appointment has been made with Dr. \_\_\_\_\_ in \_\_\_\_ days.

Date: \_\_\_\_\_ Time: \_\_\_\_\_

You have been instructed to check your blood pressure at home daily: Yes \_\_\_\_ No \_\_\_\_

Call your healthcare provider \_\_\_\_\_ Phone Number: \_\_\_\_\_

**if** your blood pressure is greater than \_\_\_\_\_ systolic (top number)

and/or

If your blood pressure is greater than \_\_\_\_\_ diastolic (bottom number)

Call your healthcare provider if:

- Your temperature is greater than 100.4.
- Your bleeding is greater than a heavy menses.
- You have any headache that is not relieved with Tylenol™ or ibuprofen (e.g., Advil™, Motrin™).
- You have pain in your belly, especially the upper area below your ribs.
- You have blurry or double vision, see spots or flashing lights.
- Your swelling is worse.
- You gain more than 3 pounds in 3 days.
- You have serious difficulty catching your breath.
- You have any new or unusual symptoms.
- You have any questions or concerns.

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**PFCC GO GUIDE v2.0**

# **The Patient and Family Centered Care Methodology and Practice**

## **The New Operating System for Health Care**



**Anthony M. DiGioia III, MD • Patricia L. Embree • Eve Shapiro  
and a Cast of Thousands of PFCC Champions, Patients and Families**

## **Viewing All Care as an Experience through the Eyes of the Patients and Families**

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# **TRANSFORM CARE IN SIX STEPS:**


The Patient and Family Centered Care (PFCC) Methodology and Practice

# THE PFCC METHOD...AMAZINGLY SIMPLE. SIMPLY AMAZING.

*Imagine this scene, with Louis Armstrong's rendition of "What a Wonderful World" playing softly in the background:*

You are a nurse, driving to the hospital for your first day of orientation. You're a little nervous, but also excited. The first sight you see is a friendly valet helping patients park their cars. "I've never seen that before," you think. Immediately you have a feeling this is going to be a good place to work. This feeling is reinforced when you walk inside and find the area looks warm and welcoming, with plants nicely arranged and art on the walls. Then you see that all the doctors and nurses smile and greet each other whenever they pass. "Wow, a friendly bunch," you tell yourself, "who seem to genuinely like each other and enjoy being here." And although the signage is clearer than any you've ever seen, your new colleagues promptly ask anyone who looks the least bit lost, "What can I help you find?" As you walk through the units you notice there are no "Waiting Room" signs. Instead, you see "Family Lounge" signs that lead to areas that look like inviting living rooms with fully stocked refrigerators, pool tables, comfortable-looking sofas and chairs, large flat screen TVs, and Internet





accessible computers. In one of these family lounges a celebration is going on—a group of patients and family members are singing “Happy Birthday” and are about to cut into a chocolate cake. As you continue on your journey through the hospital you notice state-of-the-art gyms on some of the units. When you peer into patient rooms you see that the patients and family members inside actually seem happy and at ease. “Wait,” you think, “I must be dreaming. Pinch me...am I actually in a hospital?”

“OK,” you think as you head into orientation, “this looks like a great place for patients and families, but I wonder what it’s like to work here?” As the day goes on, you sense this good feeling everywhere, as though it’s embedded in the culture. By the time the Chief Executive Officer has finished speaking, you begin to understand that this good feeling is real. It stems from the respect with which people view and treat each other, regardless of their title or position in the hospital. “There are many names for the staff who work in the hospital, and their jobs are different” the CEO had said. “But regardless of their title or their job, each is a Care Giver. Each plays a vital role in the care of our patients and families. We could not serve their many needs without the contributions of doctors, nurses, aides, technicians, dieticians, secretaries,

appointment schedulers, parking attendants, housekeepers, and others. Each ‘touches’ the patient and family in some important way. This is true of the parking attendants who greet patients and families with a smile; the kind secretaries who help patients fill out forms; the friendly housekeepers who clean patient rooms; the compassionate and attentive nurses who are always there; and the surgeons who explain procedures clearly so that all patients and families understand. And these are only those who patients and families actually see,” the CEO had said. “In addition,” she continued, “our Care Givers include financial representatives, those who order hospital supplies, medical record clerks, and hospital leaders, all of whom are Care Givers behind the scenes. So although I sit in an office most of the time and don’t usually interact directly with patients and families,” the CEO added, “I am a Care Giver!”

The next day, when you arrive for your first day in your new job, you think your supervisor must have read your mind when she confirms what you already sense—that your experience here will be different from anywhere you have ever worked. “As Care Givers in our PFCC Hospital,” she says, “we look at the care we deliver through the eyes of patients and families and aim to provide them with the ideal Care



Experience. We think about what ideal care looks and feels like to patients and families and then see whether the care we deliver really measures up. And if it doesn't, we get to work to transform it so it becomes the ideal."

Sensing your confusion, your supervisor says, "Perhaps I should start at the beginning. Our organization follows the six-step Patient and Family Centered Care Methodology and Practice (PFCC M/P) to evaluate, co-design, and transform care in partnership with patients and families.

**"We follow six steps to evaluate and transform care:**

**STEP 1** Select a Care Experience

**STEP 2** Establish a PFCC Care Experience Guiding Council

**STEP 3** Evaluate the Current State by Looking at All Care as an Experience through the Eyes of the Patient and Family, and Develop a Sense of Urgency to Drive Change

**STEP 4** Develop your PFCC Care Experience Working Group based on Touchpoints

**STEP 5** Create a Shared Vision by Writing the Story of the Ideal Patient and Family Care Experience as if You were the Patient and Family Member

**STEP 6** Identify your PFCC Improvement Projects and Form Project Improvement Teams"

*Stop the music. No, you wouldn't be dreaming. You would be in any one of the hospitals that has adopted the PFCC M/P.*

This is not your typical Care Experience. Anthony M. DiGioia, III, M.D., with the help of PFCC Partners @ The Innovation Center of University of Pittsburgh Medical Center (UPMC), has set out to transform not only patients', family members', and all Care Givers' typical hospital Care Experiences, but to transform their Care Experiences in any setting—including doctors' offices, imaging centers, laboratories, long-term care facilities, and elsewhere—into the ideal.

We've done this using our six-step PFCC M/P. Not only does the PFCC M/P transform the Care Experience of patients and families, it also changes the behavior of all Care Givers, creating a PFCC culture. The PFCC culture transforms the way Care Givers view their roles, the way they relate to each other, and the way all Care Givers define the ideal Care Experience for patients and families. The PFCC culture leads to improved patient outcomes, better quality of care, increased patient safety, and decreased waste. Explaining the PFCC M/P is the subject of this Go Guide. If we can do it, you can do it! This Go Guide will show you what the PFCC M/P involves and how you can use it, too.

Sounds too good to be true? Well, it is true. And if you're interested in finding out even more about the PFCC M/P, you can search our Web site at: [www.pfcc.org](http://www.pfcc.org).

**WWW.PFCC.ORG**

# PATIENT AND FAMILY CENTERED CARE METHODOLOGY AND PRACTICE 101

Chances are you and your colleagues deliver outstanding medical care and aim to do so in a patient and family centered way. But have you ever asked yourselves if the terrific care you are delivering really meets all the needs of patients and families? Have you ever thought and talked about—not only among yourselves but with patients and family members—what their needs really are? Have you ever wanted to improve your delivery of patient and family centered care but didn't know where to begin or how to sustain the changes you were able to make? If so, would you consider using a new paradigm for health care delivery—that is, a new healthcare Operating System—that would make patients and families true partners in health care improvement?

As Care Givers, we asked ourselves these questions and brought patients and families into the conversation. As a result we realized we needed to develop a simple, easy-to-use approach to delivering not only care, but to co-design exceptional Care Experiences, with patients and their families. This approach is the PFCC M/P, a simple performance improvement tool that builds on process improvement to enable Care Givers, through the active involvement of patients and families, to redesign the delivery of care in a complex system.

*The singular goal of the PFCC M/P is to co-design exceptional Care Experiences for patients and their families by viewing all aspects of care through their eyes.*

“I’ve heard a lot about co-designing the ideal Care Experience with patients and families,” you tell another Care Giver, “but when is the right time to engage patients and families in the process? And what are the best ways to do this?” “Two excellent questions,” she replies. “There are many ways to involve patients and families in co-designing the Care Experience. For example, we must ask patients and families if we can Shadow them throughout their Care Experience. We should invite patients and families to serve as members of the Guiding Council or a Working Group. And we can ask patients and families to serve on our Patient and Family Advisory Council. The PFCC M/P provides multiple opportunities for us to work in partnership with patients and families to co-design the Care Experience. There are no set rules. How best to do this is up to us.”

*Transforming care from the current to the ideal experience for patients, families, and Care Givers requires us all to work together as partners in change, viewing all aspects of the Care Experience*

*through the eyes of patients and families. Transforming the Care Experience takes leadership and vision, thought and planning, teamwork and commitment, and a drive toward continual improvement. Care transformation also takes a positive attitude, an urgent sense that change is both essential and possible, flexibility and adaptability, and an enthusiasm for embracing change. Having the right mindset is fundamental to transforming care.*

Dr. DiGioia, head of Renaissance Orthopaedics and PFCC Partners @ The Innovation Center of UPMC, knew that he and his colleagues could transform the delivery of care for patients and families. After successfully using the PFCC M/P to transform care in the Hip and Knee Total Joint Replacement Program at Magee-Womens Hospital of UPMC, Dr. DiGioia was ready to spread PFCC M/P to other hospitals in the UPMC system. The health system's leadership enthusiastically agreed to try it, first in the Surgical Care Experience and Level 1 Trauma Care Experiences at UPMC Presbyterian Shadyside, and then in other Care Experiences and in other hospitals. After seeing how well the PFCC M/P works to transform care, more hospitals are getting on board. You can use the PFCC M/P to transform the care of patients and families in your hospital. Start with Step 1, follow the six steps as described, and you will be on the road to care transformation.

**A sense of urgency is what drives and sustains care transformation-the urgent need not only to change care for the better but continually drive change toward the PFCC ideal.**



## STEP 1 **SELECT A CARE EXPERIENCE**

The first step is to decide which Care Experiences you are ready to transform for patients and families. For example, you may want to focus on a broad Care Experience, such as total joint replacement or trauma care. Or, you may want to start by selecting a more narrowly focused Care Experience, such as a visit to any doctor's office, the inpatient registration process, or the patient's and family's experience on the day of surgery.



## STEP 2 **ESTABLISH THE PFCC CARE EXPERIENCE GUIDING COUNCIL**

The Guiding Council is initially a small group of committed and enthusiastic Care Givers who serve as champions to start, guide, and expand your use of the PFCC M/P. As you will see, the Guiding Council starts small but then expands into the larger Care Experience Working Group. The Guiding Council is therefore essential for the launch of any Care Experience Working Group and for creating and helping to sustain the PFCC culture.

Guiding Council members are usually the first to Shadow the Care Experiences of patients and families, which allows them to map the flow of the patient's and family's Care Experience by identifying Touchpoints--the places patients and families go during the care process, for how long, and the Care Givers with whom they come into contact. The Guiding Council's Shadowing sets the stage for the Working Group's Patient and Family Shadowing and Care

Experience Flow Mapping, which will guide specific improvement projects as explained in Step 3, below.

The Guiding Council also establishes a PFCC Fund to empower Care Givers to make purchasing decisions and implement pilot projects quickly. (Details about forming Working Groups, Project Teams, and requesting funds for improvement projects are presented in Steps 4 and 6.)

### **IDENTIFY PFCC CHAMPIONS: INCLUDING CLINICAL CHAMPIONS, ADMINISTRATIVE CHAMPIONS, AND A PFCC COORDINATOR**

The Guiding Council should include different types of PFCC M/P Champions, each with the seal of approval from the top of the organization to lead change:

- Administrative Champions, such as Managers, Directors, a Vice President, Chief Operating Officer, or Chief Executive Officer whose involvement will put the hospital's stamp of approval on your use of the PFCC M/P.
- Clinical Champions or, for those who prefer to share Guiding Council responsibilities, Co-Champions, who will inspire colleagues to make and sustain needed changes. In the case of non-clinical departments, such as human resources, housekeeping, food services, or valet parking, the people in this role are called, simply, Champions.
- A PFCC Coordinator, who serves in multiple roles, including coordinating the essential activity of Patient and Family Shadowing (explained in Step 3), as well as scheduling meeting rooms, sending updates, ensuring the prompt flow of information to all involved in the PFCC M/P, and maintaining lists of active, completed, and future projects (described in detail in Step 6b). The role of coordinating Shadowing may be shared by the other PFCC Champions.



**TIP**

***Members of the Guiding Council should complete Steps 1 through 4 as a team.***

To get started, the Guiding Council needs to meet for only 30 minutes each week, at the same time every week.



**CONTINUED** --->

“Why is a Guiding Council important?” you ask. “Well” explains your supervisor, “As you’ll see, the Guiding Council plays a number of essential roles, including setting the stage for Working Group formation and membership. The Guiding Council is responsible for team building—both in terms of establishing Working Groups and serving as resources for Working Group and Project Team members. The Guiding Council also begins to develop the Shadowing and Care Flow Mapping programs to see which segments of entire Care Experiences are in greatest need of transformation from the patient’s and family’s perspective. In addition, a pivotal role of the Guiding Council is to establish a PFCC Fund and an approval process to guide care transformation efforts and test pilot projects.” “I understand,” you say, “the Guiding Council is the hub of the care transformation process.”



**TIP**

***It is essential for your Champions to be good leaders, good listeners, and be well respected by colleagues.***



**STEP**

**3**

**EVALUATE THE CURRENT STATE BY LOOKING AT ALL CARE AS AN EXPERIENCE THROUGH THE EYES OF THE PATIENT AND FAMILY, AND DEVELOP A SENSE OF URGENCY TO DRIVE CHANGE**

An essential step in the process of care transformation is to *view all Care as an Experience through the eyes of patients and families*. Step 3 uses tools to help

you gather information about the way patients and families actually experience their care during every crucial “Touchpoint” and to help you learn how they feel about it. A Touchpoint is any key moment or place in the health care setting where patient and family Care Experiences are directly affected by any Care Giver. The information-gathering tools used at each Touchpoint include Patient and Family Shadowing and Care Experience Flow Mapping, Patient and Family Storytelling, Patient and Family Surveys (including but not limited to the Hospital Consumer Assessment of Healthcare Providers and Systems [HCAHPS]), and other reports of patient satisfaction. Of these tools, Patient and Family Shadowing and Care Experience Flow Mapping are requirements of the PFCC M/P. Using these and the other low-tech, low-cost tools that are part of the PFCC M/P will yield information that will keep you on the path to care transformation.

“The word ‘Touchpoint’ is so evocative,” you tell a colleague. “On one level it refers to any Care Giver, in any department, who comes into contact, or ‘touches,’ a patient or family member. But on another level,” you continue, “it encapsulates what the PFCC M/P is all about—a true and meaningful connection with patients and families that comes from seeing care through their eyes.”

## A. PATIENT AND FAMILY SHADOWING AND CARE EXPERIENCE FLOW MAPPING

**Patient and Family Shadowing** is the direct, real-time observation of patients and families as they move through each step of a Care Experience. The Shadower is the person who conducts the Shadowing. The Shadower is charged with seeing the Care Experience through the eyes of the patient and family, recording every step of the Care Experience, and constructing the Care Experience Flow Map. The Care Experience Flow Map details the Touchpoints, showing where patients and families go during the care process and the Care Givers with whom they come into contact. (Identifying Touchpoints through Care Experience Flow Mapping will also help you decide which Care Givers



should participate in PFCC M/P Working Groups and Project Teams.) Care Experience Flow Mapping can be eye-opening, causing you to ask, “How can we improve every step of the Care Experience?” After Shadowing and constructing the Care Experience Flow Map, the Shadower reports his or her observations back to the Working Group as explained in the booklet *Go Shadow, View and Co-Design Exceptional Care Experiences: Your Guide to Patient and Family Shadowing With Patients, Families and Care Givers* ([www.pfcc.org/Go-Shadow](http://www.pfcc.org/Go-Shadow)).

Patient and Family Shadowing will allow you to:

1. Observe the steps in the care process as they happen, including how long each step takes
2. Record and understand the patient’s and family’s reactions to what happens at each step
3. Map the flow of care for patients and families, creating the Care Experience Flow Map

To Shadow patients and families, define where the Care Experience you want to observe begins and ends, and follow patients and families along this defined pathway throughout the care process. (Defining where the Care Experience begins and ends is also a responsibility of the Guiding Council.) You can Shadow either an entire Care Experience at one time, or Shadow segments of a Care Experience at different times to build a complete story. Note where patients and families go and for how long, observe their experiences, and record their reactions.

For example, you may choose to Shadow a patient and family during their doctor’s visit, starting from the time the patient and family arrive to park their car until the time they drive away after their visit is completed. In the case of such a narrowly defined Care Experience, Shadowing the entire Care Experience at one time can be accomplished easily. However, if the Care Experience takes place over a longer period of time or involves a greater number of components—for example, an Emergency Room Care Experience followed by a hospital stay—it would be easier for more than one Shadower to Shadow this Care Experience and to do so in segments, combining all of your observations when you are done. Whether you are Shadowing an entire Care Experience at once or Shadowing the Care Experience one segment at a time, note where patients and families go and for how long, observe their experiences, and record their reactions.

Consider establishing a Shadowing Club—a pool of people to call on to Shadow patients and families as needed, starting with members of the Guiding Council. Other members of the Shadowing Club may include other Care Givers, Care Givers assigned to light duty, new employees, volunteers, or

students in college and schools of the health professions. Such observers have “fresh eyes” and few preconceptions or biases. Plus, using interns, students, or volunteers can be inexpensive or free.

*Together, Shadowing and Care Experience Flow Mapping make it possible to co-design the Care Experience in partnership with patients, families, and Care Givers—think of it as having the input of a real-time Patient and Family Advisory Council. These tools create a sense of urgency—and a sense of direction—for Care Givers to drive change and to continue involving patients and families in co-designing the Care Experience.*

Patient and Family Shadowing will help you see both what is good and what is not so good about the Care Experience. Most importantly, Patient and Family Shadowing will reveal opportunities for improvement. Did a nurse explain a procedure clearly and completely, easing a patient’s anxiety? Or did a patient wait too long for care or information in one department? If patients and families are satisfied with their care, of course you want to know about it. But if they are dissatisfied or anxious about any aspect of their care, knowing about it quickly becomes a matter of urgency—because you and your colleagues will want to do something about it, and fast!

“Now I get it,” you realize. “I’ve just had that ‘Aha!’ moment. Shadowing patients and families points us to specific areas where we can improve, such as places where breakdowns in communication and transitions of care between services occur. Shadowing also highlights inefficiencies and redundancies in the system, reduces waste, and allows us to hear and observe the effects these have on patients and families. It’s so simple and makes so much sense, why doesn’t every hospital do this?” you wonder.

When you take a hard look at where patients and families go and with whom they come into contact, you realize that some of what you’ve been doing may be unnecessary. You may realize there is some redundancy you can eliminate or process you can streamline. You may also find there are things patients and families say you are doing well—in which case, keep on doing what you’re doing!

“We watch what people do (and do not do) and listen to what they say (and do not say). The easiest thing about the search for insight—in contrast to the search for hard data—is that it’s everywhere and it’s free.” -*Tim Brown, Change by Design*

**OBSERVATIONS**



**EMPATHY**



**INSIGHTS**

*Tim Brown, Change by Design*

## **B. PATIENT AND FAMILY STORYTELLING**

Another way to help us understand the Care Experience from the patient’s and family member’s point of view is to ask them to tell us about it as completely as they can. Patient stories, whether written down—or, even more powerfully, captured on audio or video recorders—can supplement surveys by allowing patients to explain why they feel the way they do about the care they’ve received, how it can be improved, what went well and what didn’t go so well, what is most important to them, and so on. Patient stories can provide you with information that surveys alone cannot easily capture. There is no better way to find out how a patient or family member really feels.

In addition to asking patients and families to tell us about their Care Experiences directly, there are other ways to capture the Care Experience as seen through their eyes. Ask former patients who can



serve as volunteers and “mentors” to new patients. Ask members of your hospital’s Patient and Family Advisory Council to talk about their Care Experiences and the stories others have shared with them (anonymously, of course).

“I was just thinking back to the time, two years ago, when I was a patient,” you tell a co-worker, “and what I would have told the doctors and nurses if only they had asked me. It wasn’t that my medical care wasn’t good—it was. But I would have given anything for the chance to just take a shower or brush my teeth! Given everything else they were dealing with, I understand why my personal hygiene didn’t seem to be their top priority—but it certainly was one of mine. Having been a patient has made me aware that patients and families often have needs we Care Givers don’t realize. So we definitely need to ask them, listen, and respond accordingly. What I really mean,” you add, “is that in addition to being Care Givers, we are also patients ourselves, or the family members of patients. We know what being a patient or the family member of a patient feels like. Drawing on those experiences helps us to see the Care Experience from the patient’s and family’s point of view.”

### C. INFORMAL PATIENT AND FAMILY SURVEYS

One of the best ways to learn how patients and families really feel about their care is to ask them to complete short, simple, focused surveys about every aspect of their Care Experience. This can include parking, wayfinding, waiting for care and information, nursing care, the friendliness of the Care Givers, the cleanliness of the hospital, the communicativeness of the surgeon and anesthesiologist, the noise level—and don’t forget to ask their opinions about the food. Their answers will help you see all of the Touchpoints through their eyes. What you learn will help guide you on your care transformation journey.



***Customize focused patient surveys based on specific Care Experiences. Re-use these surveys to gauge change. Always evaluate and re-evaluate your progress—using all tools in the PFCC M/P—over and over again.***



“You think,” says Suzanne Rocks, R.N., “I’ve been a nurse for 25 years. I know what patients and families want and what they don’t want. You believe this,” she continues, “because you live it and work it every day. But I found out from tallying the results of these surveys that there are some things that are more important to the patients than I thought. For example, I didn’t realize how many people were having a hard time just finding my unit. Or that parking was such a big issue.”

#### **D. GATHER EXISTING REPORTS, SUCH AS THOSE ON PATIENT SATISFACTION, AND HCAHPS SURVEYS**

Gathering existing reports on patient satisfaction will tell you what patients think about their Care Experience as a whole, as well as what they think about specific aspects of their Care Experience. Patient satisfaction surveys and HCAHPS surveys (HCAHPS surveys are available free of charge at <http://www.hospitalcompare.hhs.gov>) ask patients questions about their perceptions of the care they received while in the hospital. The HCAHPS survey will tell you how patients rated such things as getting through to the office, ease of making appointments and finding their way, waiting times, cleanliness, courtesy of all the Care Givers, teamwork of health care providers, explanations of procedures, and more. Reviewing HCAHPS survey scores for your hospital, along with focused reports of patient satisfaction, will help you to see which patient experiences are in greatest need of transformation. Reviewing these surveys will also allow you to compare patients’ ratings of your hospital with their ratings of other hospitals nationwide.



***Focus on transforming the Care Experience for patients and families using the PFCC M/P, not just on improving survey scores. Patient satisfaction and HCAHPS scores will rise as a natural result of focusing on improving the patient and family Care Experience.***

## STEP 4

### DEVELOP YOUR PFCC CARE EXPERIENCE WORKING GROUP BASED ON TOUCHPOINTS

#### A. USE THE CARE EXPERIENCE FLOW MAP TO IDENTIFY YOUR WORKING GROUP MEMBERS

When you have completed the first part of Step 3, mapping the flow of care to clarify Touchpoints and Care Givers, your Guiding Council will be ready to invite Care Givers to serve on a Working Group to transform the selected Care Experience.

To serve on the Working Group, the Guiding Council selects Care Givers who represent each Touchpoint, or each department with which patients and families come into contact. Working Group members include physicians, nurses, aides, those who work in the operating room, therapists, social service providers, dietitians, parking attendants, those who work in information technology, pharmacists, and others as needed.

*Being part of a PFCC Working Group leads to a culture of ownership among all Care Givers involved in the PFCC M/P. The key to a culture of ownership is the power of Care Givers—from all levels and all areas of the organization—to make decisions and co-design change in partnership with patients and families.*

“The people meeting in these groups can make things happen and make them happen quickly,” says Suzanne Rocks, R.N. “You will have people from multiple departments all over the hospital meeting together, including the IT department, housekeeping, and more,” she continues. “If something comes up that is a problem in one department, the person representing that department can take it back and say, ‘This is a high-level group...everyone is looking at everything they’re doing...we have to get this fixed.’”



## B. PLAN AND SCHEDULE THE KICK-OFF MEETING FOLLOWED BY WEEKLY MEETINGS

The Guiding Council should invite those who have been chosen to serve on the Working Group to a kick-off meeting. Send an invitation in the form of a letter from the CEO, Vice President, or the Chief Nursing Officer. The letter should briefly explain what the PFCC M/P is, invite them to participate in a Working Group, and invite them to attend the kick-off meeting.

Prepare a packet of information for kick-off meeting participants. The packet should include information about what the PFCC M/P is all about, along with the results of your Patient and Family Shadowing, Care Experience Flow Mapping, and any other evaluations your Guiding Council has conducted to help you understand the current state of patient care. Presenting the results of Patient and Family Shadowing at your first Working Group meeting is especially important to create a sense of urgency to drive change, since the Shadowing report will clearly show how patients and families see, and what they feel about, every aspect of their Care Experience. At the kick-off meeting, the Administrative and Clinical Champion welcome attendees and make brief opening remarks. Guiding Council members then explain the six steps and the goals of the PFCC M/P.

Hold the kick-off meeting the same day and time of the week you plan to hold weekly Working Group meetings. Have your upcoming Working Group meeting dates scheduled at the time of the kick-off meeting, if possible. Setting meeting dates and times for a year in advance helps to create a sense of urgency and sends the message that this is an important commitment your Guiding Council is determined to sustain.



***Having the Guiding Council meet immediately after each Working Group meeting will facilitate debriefing and the strategizing of next steps.***

“This is amazing,” you think. “I’ve never sat in one room with so many people from so many different areas of one hospital. On my left is a physician and on my right, a housekeeper. And no matter how different our backgrounds are,” you tell yourself, “we are here with a single purpose: to brainstorm how to deliver care that really meets the needs of patients and families.”

## C. EXPLAIN THE PFCC FUND AND APPROVAL PROCESS GIVING THE WORKING GROUP AUTHORITY TO INVEST IN PFCC PILOT PROJECTS...QUICKLY.

Empowerment is a key concept of the PFCC M/P, and this includes fiscal empowerment. The Guiding Council, having established the PFCC Fund, should present the details of this Fund to the Working Group at the kick-off meeting.

Project Teams will have the authority to spend up to a certain amount of money on care transformation projects, which allows them to start and complete pilot projects quickly. To spend more, they need administrative permission. (See Step 6.5 for details on the budget approval process for Project Teams.)



## **STEP 5** **CREATE A SHARED VISION BY WRITING THE STORY OF THE IDEAL PATIENT AND FAMILY CARE EXPERIENCE AS IF YOU WERE THE PATIENT AND FAMILY MEMBER**

Using the PFCC M/P means patients aren't the only ones who get to tell stories. Storytelling is at the core of the PFCC M/P and is used by everyone involved in transforming the patient's and family's Care Experience, including Care Givers. Writing the ideal patient and family Care Experience enables you to put yourself in the shoes of patients and families. This should be easy to do if you remember that you are not only a Care Giver, but at some point you have also been a patient or the family member of a patient. What did your Care Experience at that time feel like? Remembering your own Care Experience will help you to imagine and write the ideal experience from the patient's and family's point of view.

Picture John Lennon's song "Imagine" playing in the background as you read about and prepare to take Step 5:

Imagine what ideal care would look like in the perfect hospital, in a perfect world. Then write it down in the form of a story. Don't be constrained by costs or by other considerations—after all, this is your dream! It doesn't matter what your role or position is in the hospital. If you are a parking attendant, a surgeon, a housekeeper, a dietician, or a nurse, what does the ideal Care Experience mean to you? Through discussion and sharing of individual stories, "your story" becomes "our story," the collective story and shared vision of the Working Group.





***Writing the story of the ideal Care Experience helps you visualize the details of ideal care and sets the stage for your PFCC Care Experience improvement projects.***

Writing the story of the ideal Care Experience also contributes to team building and knocks down artificial silos. For example: Imagine you get a call from the hospital telling you your mother just arrived in an ambulance after having been in a car crash. You drive right over, panicked and frightened. How should your mother be cared for? How should you be cared for? Write a story in which you both experience ideal care. Think about each Touchpoint and Care Giver, every person with whom your mother and you would come into contact. Think about every process each of you would have to go through. What should the ideal Care Experience look and feel like to both of you, every step of the way?

Now, compare your ideal with what currently happens: How closely does your ideal Care Experience match the current Care Experience of patients and families in your hospital? If current care and the ideal are not the same, what can you do about it? The steps you can take to bring the ideal Care Experience into alignment with what currently takes place will define your Care Experience improvement projects.



***Making and maintaining lists of Care Experience improvement ideas is an essential part of transforming the Care Experience for patients and families.***

## STEP 6

### **IDENTIFY YOUR PFCC IMPROVEMENT PROJECTS AND FORM PROJECT IMPROVEMENT TEAMS**

#### **A. IDENTIFY POTENTIAL PROJECTS BY COMPARING THE CURRENT STATE TO THE IDEAL PATIENT CARE EXPERIENCE AS PRIORITIZED BY PATIENTS AND FAMILIES**

At your Working Group meeting, members should use feedback from patients and families collected during Patient and Family Shadowing, Care Experience Flow Mapping, Patient and Family Storytelling, and from patient and family surveys--to identify, list, and prioritize the Working Group's projects. Based on the frequency with which patients and families cite problematic areas, common themes may emerge. For example, if patients and families say they get lost trying to find their way around the hospital or that they have to wait too long in particular areas, their comments will tell you where your priorities for improvement projects need to be. When you determine where improvement projects fit within particular Care Experiences, you will be ready to form Project Improvement Teams to address them.



***Use step 6 as a road map that will help you gain and sustain momentum to transform the current into the ideal Care Experience for patients and families.***

“During your first Working Group meeting, a skeptical colleague leans over and whispers, ‘If it ain’t broke, why fix it?’ To which you respond, ‘If you think it ain’t broke, you haven’t looked at it closely enough through the eyes of patients and families.’”

#### **B. FORM PFCC PROJECT IMPROVEMENT TEAMS TO BEGIN THE “CYCLE-WITHIN-A-CYCLE” AND CHANGE THE CULTURE.**

When your Working Group has made a list of projects, Working Group members can volunteer to



**CONTINUED -->**

serve as Project Improvement Team Co-Leaders to begin the work of care transformation. Project Improvement Team Co-Leaders can then recruit team members from both inside and outside of the Working Group to develop, test, implement, and evaluate the results of pilot projects. Project Improvement Team members should include Care Givers who can help to transform the Care Experience for patients and families based on the Care Experience Flow Map for their project.



***Project Improvement Team Co-Leaders should recruit members for the Project Improvement Team based on Care Giver Touchpoints identified through Patient and Family Shadowing and Care Experience Flow Mapping.***

Invite Care Givers from inside and outside the Working Group, striving for a 50/50 mix. Pull in Project Improvement Team members from anywhere in your organization as needed. For example, involve graphic artists to be part of your Project Improvement Team if your goal is to improve signage.

Project Improvement Teams follow the same six steps of the PFCC M/P, making the work of Project Improvement Teams a “cycle within a cycle”:

**STEP 1.** Select a Project based on the Perspectives of Patients and their Families

**STEP 2.** Assign Project Team Co-Leaders

**STEP 3.** Evaluate the Current State by Using Care Experience Flow Mapping, Patient and Family Shadowing, Patient Storytelling, and Patient and Family Surveys—Viewing All Care as an Experience through the Eyes of the Patient and Family

**STEP 4.** Recruit Members for the Project Team based on Care Giver Touchpoints identified through Care Experience Flow Mapping

**STEP 5.** Create a Shared Vision by Writing the Story of the Ideal Patient and Family Care Experience for the Project as if you were the Patient and Family Member

**STEP 6.** Get to Work....

As noted above, one of the tasks of new Project Improvement Team members is to write their story of the ideal patient and family Care Experience, focusing on a specific segment of care. Just as the Working Group identified gaps in the current, compared with the ideal Care Experience, of patients as described in Step 5, the Project Improvement Team will do the same within the scope of their focused



projects. The gaps that emerge between the current and the ideal state will reveal where the Project Improvement Team should begin their improvement efforts. Project Improvement Team members then create a “To Do” list for each project and roll up their sleeves to get the work done.

At the weekly Working Group meeting, Project Improvement Team Co-Leaders report on the status of their active projects. Project Improvement Team Co-Leaders keep the momentum of the Project Improvement Team going by ensuring the Team meets at least weekly and reports on its progress each week to the Working Group.

The following “Rules to Play by” will help Project Improvement Team members stay focused and sustain momentum for care transformation.

## PROJECT TEAM RULES TO PLAY BY...

### 1. PROJECT IMPROVEMENT TEAMS MEET EACH WEEK (OUTSIDE OF THE WORKING GROUP) AND REPORT TO THE WORKING GROUP AT WEEKLY MEETINGS

Weekly meetings of Project Improvement Teams are essential for creating and sustaining the sense of urgency and the momentum necessary to transform the Care Experience for patients and families. By facilitating continual dialogue, weekly meetings help Project Improvement Team and Working Group members cross the communication chasm and work closely together to become “high performance” care teams.

### 2. FOCUS ON EASY-TO-DO, LOW-TECH SOLUTIONS TO START

To help you prioritize your pilot projects, begin by focusing on improvements involving easy-to-do, low-tech, low-cost solutions. The positive results will generate excitement for the transformation process and keep the momentum of your Project Improvement Team and Working Group going.



***The Guiding Council should encourage the Working Group and Project Teams to start with easy-to-do projects that will have a high impact at low cost.***



“Do you know what our Guiding Council first suggested to our Working Group as a low-cost, high-impact project?” you ask. “It was creating a few temporary signs letting patients and families know where information sessions they needed to attend were taking place. We noticed immediately,” you continue, “that people were not confused; they knew where they had to go. Such a little, inexpensive change made such a big difference. The success of this project made us want to see what else we could improve!”

### **3. PROPOSE PILOT PROJECTS AND CREATIVE SOLUTIONS...AND DON'T BE AFRAID TO FAIL, BECAUSE YOU WILL LEARN A LOT!**

The Working Group generates ideas for pilot projects and a timeframe for their completion. The timeframe for completion varies—sometimes members of a Project Improvement Team think a week will be enough time to make a change and evaluate its effects; other times they think it might take a month. When your evaluation shows your pilot project is working, you can bring it to the Working Group to discuss spreading it to other areas of the hospital.

“Someone on one of the Project Improvement Teams had the creative idea of putting white boards opposite from the patient beds in one unit so patients and families would know what their care plan is for the day,” you recall. “It seemed easy to do, inexpensive, and we could start it right away! The Working Group thought it was a great idea and said, ‘Go for it!’ After one week so many patients and families told us they were relieved to know what was going on,” you continue, “that we bought white boards for every patient room in the hospital.”



***Use “Spotlighting,” in which Project Improvement Teams give presentations of their pilot projects to the Working Group. Spotlighting allows Project Improvement Teams to receive advice and input from Working Group members.***

#### **4. SEND WEEKLY UPDATES TO THE PFCC COORDINATOR, WHO WILL MAINTAIN LISTS OF ACTIVE, COMPLETED, AND FUTURE PROJECTS FOR PROJECT IMPROVEMENT TEAMS AND THE WORKING GROUP**

The Project Improvement Team Co-Leaders send weekly updates to the PFCC Coordinator, who maintains three lists of projects, as explained below:

- A list of Current Projects
- A list of Completed Projects
- A list of Future Projects

The list of Current Projects, which is discussed at weekly Working Group meetings, shows which projects are being actively worked on by Project Improvement Teams. The list of Current Projects briefly states the current status of each project and what the Project Improvement Teams have accomplished so far.

When a Project Improvement Team completes a project, the PFCC Coordinator moves the completed project to the list of Completed Projects. Tracking Completed Projects will remind you of all your achievements, help to build and sustain momentum, serve as a measure of the Working Group's performance, and motivate you to keep going to overcome new challenges. In addition, lists of Completed Projects come in handy for passing on to other Care Experience Working Groups in the future.

Always capture ideas for projects on a master list of Future Projects. Keeping track of Future Project ideas will generate new projects as current projects are completed. This is a continual opportunity for improvement, since we will always be striving to reach the ideal in any Care Experience.

Because projects are fluid, one of the PFCC Coordinator's essential roles is to keep these lists up-to-date.

#### **5. IF FUNDING IS NEEDED, PRESENT PROPOSALS TO THE WORKING GROUP FOR APPROVAL USING THE PFCC FUND**

As mentioned in Step 2, the Guiding Council establishes a PFCC Fund and an approval process for care transformation efforts. The Guiding Council gives Project Improvement Teams the authority to



spend up to a certain amount of money on care transformation pilot projects, which allows them to start and test projects efficiently. When Project Improvement Teams need funds for proposed projects, the Project Improvement Team Co-Leaders present a one-page proposal at the weekly PFCC Working Group meeting, explaining:

1. What the project is
2. What the funds will be used for
3. How much the project will cost
4. How the project will measure its effectiveness after implementation
5. The timeframe for the pilot project (usually three to six months)

If the cost of the proposed project is lower than the ceiling the Guiding Council has set, the Working Group can approve it. If the cost is higher, the Administrative Champion takes the Project Improvement Team's proposal to the CEO or Executive Management Group for approval or disapproval. If the project is denied initially, the CEO or a representative of the Executive Management Group explains the reasons for the denial. The Working Group and Project Improvement Teams then brainstorm ways to address concerns. If the pilot project is implemented successfully, future costs should be supported by normal operations.



***It is important to create an account where funds spent on PFCC M/P transformation efforts can be tracked and reported easily.***

“Working Group and Project Improvement Team members try to push people to do the best they can with the resources they have,” you observe. “We are good about being fiscally responsible,” you think, “which often leads to our finding creative, low-cost, low-tech solutions that we can test right away.”

## 6. MEASURE AND EVALUATE YOUR CHANGES

You can't change what you don't measure. So when you make changes—both in the pilot stage and after operationalizing changes more widely—evaluate, evaluate, evaluate the Care Experience by using all tools that are part of the PFCC M/P—Patient and Family Shadowing, Care Experience Flow Mapping, Patient and Family Storytelling, and Patient and Family Surveys. You can also evaluate the effectiveness of your projects by tracking changes in costs, patient survey responses, waiting times for patients and families, length of stay, and other measures.

Ask patients to respond to surveys, continue to Shadow patients' and families' Care Experiences, and ask them to write comments and their stories about how they feel about their care. The changes you make are only as good as patients and families believe they are. Ask them every so often to tell you what they think about different aspects of their care. Something that seemed to work well for patients and families one year may not work as well the next.

“One year,” you explain, “our Project Improvement Team had the idea of using coaster pagers—you know, the kind some restaurants use—to let patients know when it was their turn to be seen. Patients and families loved them because they no longer needed to sit in one area and wait their turn. The coaster pagers gave them a little more freedom to move around. When we asked how they liked the coaster pagers the next year, they hated them! Why? Because by this time we had installed video monitors that told patients and families exactly where patients were and where they would be going at any given time. This meant they had even more freedom now than they did before. Patients and families told us the pagers were now unnecessary, kind of a nuisance, and were a good way to spread germs. But we would not have known this if we hadn't asked.”

## 7. PROJECT IMPROVEMENT TEAMS CAN DISBAND IF THEIR WORK HAS BEEN COMPLETED OR TEAMS CAN RE-FORM TO ADDRESS NEW PROJECTS. BUT PFCC WORKING GROUPS ARE FOREVER...

Project Improvement Teams can be disbanded when projects are completed and new Project Improvement Teams can be formed when the Working Group decides to make future projects active ones. The PFCC M/P relies on the continual gathering of information from patients and families, and making the needed changes in response, including changes in Project Improvement Teams.

# CONCLUSION

*“It takes a lot of work to make something simple, to truly understand the underlying challenges and come up with the elegant solutions.” - Steve Jobs*

**PFCC M/P is the performance improvement tool that not only will transform the Care Experience of patients and families, it will also change the behavior of all Care Givers, creating a PFCC culture. Changing the culture will, in turn, lead to improved patient outcomes, better quality of care, increased patient safety, and decreased waste. In such a culture, it is second nature to continually seek ways to improve the Care Experience for patients and families. PFCC is no longer what you do, it is who you are.**

**Think of PFCC as a circle that never ends, as opposed to a straight line that goes from start to finish. Think of Project Improvement Teams as mini “tornados” of change.**



*Imagine the theme from the movie “Rocky” streaming in the background: Does all this sound too good to be true? Well, according to our Care Givers, it is true.*

Ask Jennifer, a nurse, who says, “The PFCC M/P reminds me of why I became a nurse in the first place.” Or Dan, a physician, who says, “I was skeptical at first. But our PFCC M/P Working Group has achieved results beyond all my expectations!”

Tom, a pharmacist, says, “Because of the PFCC M/P I now work more closely not only with my colleagues, but with patients and families. This personal contact is professionally satisfying for me.”

According to Kevin, a valet parking attendant, “As the first person patients and families see when they drive up and the last person they see when they leave, I take pride in knowing I am important in making them feel comfortable and welcome.”

Rhonda, a CEO, says, “We’re all in this together—Care Givers, patients, and family members. Each of us has been or will be a patient or family member at one time or another. The PFCC M/P shows us how to deliver ideal Care Experiences as patients and families define them.”

And Tina, a dietician, exclaims, “Taking care of patients and families is the PFCC M/P; we are obligated to listen and to act!”

And how do our patients and families feel? Here is what just a few of our ‘raving fans’ have to say:

*“My experience at Magee-Womens Hospital met every expectation, and then some. Each person involved in my care was exceptional. Thank you for my care and congratulations on attaining perfection.”*

*“The compassion, kindness, and understanding of the office staff and nurses were extremely impressive. During my hospital stay the nurses didn’t seem rushed. They took the time to talk to me and I really felt taken care of. Thank you.”*

*“My family and pastor were welcomed with open arms and were treated with the same compassion as I was.”*

*“Dr. DiGioia and his team performed with skill, care, and diligence. They each did their best to fulfill a commitment to excellence.”*

*“If you must be in a hospital, then this is the one you want to be in!”*

Don’t stop the music—keep it going, knowing that care transformation is within your reach. All it takes is focused commitment, a drive toward excellence, and the six-step PFCC M/P!



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And a Cast of Thousands of PFCC Champions, Patients and Families at  
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