



Guide for Engaging Patients and Family in Severe Hypertension in Pregnancy/Preeclampsia Debriefing

The Florida Perinatal Quality Collaborative, Hypertension in Pregnancy Advisory Group has determined that having patient and family involvement in the review of severe hypertension and other sentinel events would be beneficial to improving the delivery of health care. Because it is sometimes a challenge to find ways to effectively engage patients, this guide was developed.

BACKGROUND

The Agency for Health Care and Research and Quality (AHRQ) reports that “research shows that when patients are engaged in their health care, it can lead to measurable improvements in safety and quality. Working with patients and families as advisors at the organizational level is a critical part of patient and family engagement and patient- and family-centered approaches to improving quality and safety. Patient and family advisors are valuable partners in efforts to reduce medical errors and improve the safety and quality of health care.” There are a variety of tools that assist facilities and providers in bringing the perspectives of patients and families into planning, delivery and evaluation of health care and AHRQ has one of these tools available on their [website](#).¹

Other organizations have also looked at practical approaches to involving patients in multiple levels of health care ranging from direct patient care and shared decision making for treatment, to outreach to patients and consumers for input on the development of systems that are responsive to a variety of patient needs, and lastly to a community level of involvement in the development of policies, laws and regulations for public health and health care.² In order to accomplish this type of involvement, organizations must assure that their structure and culture promote involvement through conscious and consistent efforts.

Hospitals and care systems can partner with consumers through planning, developing, improving, and assuring high quality, safe healthcare. Some facilities do this by using advisory councils that include consumers and work with management and management councils/committees in order to include patient and family perspectives into all aspects of operation. This requires that the culture of the facility is supportive and engaging, and may include incorporating expectations of behavior into the job descriptions and orientation of staff. Other strategies may include using consumers as a part of faculty for staff training, having staff follow patients as they experience services, and creating opportunities for patients to provide feedback. All of this is a long term process and must include commitment of leadership so that the mission, vision, values, and behaviors are consistent with the actions of the organization and that strategies are regularly reviewed for effectiveness. Several tools are available to assist in this journey.³

In order to drill down to the elements closest to the needs of patients, facilities should not just depend on their Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) results to enhance understanding of how patients view their current experiences. Such surveys need to be supplemented with specific feedback about care received. Patient focus groups are one way to solicit input in a non-threatening and supportive environment. To glean input at a more personal level, leaders can round on patient floors with specific goals of gathering patient input, especially in response to adverse events or unusual circumstances. The women themselves and even their family members can be encouraged to submit their narrative in writing. Strategies such as these allow the team to tell the patients’ and families’ stories in a powerful way and help find gaps or opportunities for improvement. In some places, these stories are a regular

part of report and organizational meetings, additional mechanisms for including patient feedback into the structure of the organization can be developed. Each organization will need to determine the appropriate steps and strategies to fit with their organization. Some external factors to consider as these strategies or programs are developed include: demographics, educational levels, health literacy, socioeconomic status, housing, violence, community resources, and support networks because they bring important insights about the population served and how they might be engaged.⁴

Generally patient safety efforts involving consumers have focused on three areas: detecting adverse events, empowering patients to identify conditions that need to be addressed, and including patients to improve the culture of safety. In all cases, it is important to guarantee patients understand that their feedback is valued, will be utilized in efforts to improve patient outcomes, and will not impact delivery of their care in the future. Patients should also be ensured that their involvement will not punitively impact specific staff members.

Inpatient focused studies have found that patients report errors that were not detected through usual surveillance such as chart review. A variety of efforts are under way to encourage patients and their families to actively engage in their own safety. AHRQ and The Joint Commission and organizations like PFCC partners (Patient & Family Centered Care) have developed initiatives to encourage patients to speak up and ask questions; these tools may be helpful as facilities develop their programs.^{5,6,7}

Other ways to solicit feedback and incorporate it into the system of care is to have patients and families review literature and materials. This review provides feedback on language, perception and understanding of the material. Additionally, the concept of “teach back” (having the recipient of education tell the person teaching what they understood to be the message or instruction given) can be used to determine understandability and the reliability of the way the information was conveyed to the individual. Fathers can sometimes be left out of the feedback loop in maternity settings. It is important to find ways to include them in the mechanisms used and to make them feel comfortable in sharing their experiences.

RECOMMENDATIONS FOR QUALITY IMPROVEMENT FOR HYPERTENSION IN PREGNANCY

1. Facilities are encouraged to utilize a multidisciplinary process of reviewing all cases of severe maternal morbidity (ACOG, AWHONN and The Joint Commission have issued definition and recommendations for this process) and utilize findings to refine processes and improve care and safety. Bring the patients’ and families’ perspectives into these reviews.
2. Develop a process locally of reviewing all cases of severe hypertension in pregnancy. A debriefing guidance document is available at the FPQC website. The terminology and style of the review may be adjusted to meet local needs, for example some facilities have named this the Patient Safety Meeting, a Post-Huddle, or have incorporated the debrief process into a daily or shift routine. Utilize the team feedback in maintaining a culture of safety and high quality by sharing successes with the team and addressing opportunities for improvement. Highlight the input of patients and families in these debriefs.
3. To gather patient and family feedback a variety of strategies may be employed. Some examples include:
 - a. Nurse Leader (Charge Nurse or Manager) or Patient Advocate that is not connected to the care of the patient can round on patients who experienced severe hypertension in pregnancy sometime after the event and have specific focused questions to ask her and her family. A Rounding sheet could be developed to assist in this process and added to the debrief sheet so that patient and family feedback is considered in the debrief process.
 - b. Develop a post discharge survey process and story-telling process for all patients who experienced a severe hypertension in pregnancy event.
 - c. Host a mother/baby group event regularly on the postpartum floor to explore patient perspectives; consider separate groups for mothers who experienced an adverse event.

- d. Host an event for dads and or family members regularly on the postpartum floor to explore their perspectives; consider separate groups for families who experienced an adverse event.
 - e. Involve patients and families in simulation training; include her observations and feedback in the debrief.
4. Sample questions that could be incorporated into group or rounds (some facilities utilize tablets in their rounds and these questions could be added there, others might opt to use a card to facilitate discussion, and others may want to make a post card that could be included in discharge materials and returned later):
- a. Did staff explain things in a way you and your family could understand at the time you needed? If not, what would have been more helpful?
 - b. Where you kept informed regarding changes in your condition? If not, who would have been the best person for us to communicate with?
 - c. Did you feel listened to when reporting concerns? If not, please explain.
 - d. Did you or your family feel included in decision-making regarding your plan of care?
 - e. Did you experience any symptoms or have any interactions with healthcare providers in the days or weeks leading up to your hospital admission that may be relevant to your pregnancy? If yes, please explain.
 - f. Are there other things you would have liked to have staff be aware of about your care?
 - g. Would you be willing to complete a follow up survey approximately 8 weeks after your discharge from the hospital? If yes, please go to this link: _____ and provide additional feedback (provide a postcard with this information and/or comment card to be returned to the facility.)

References:

1. Guide to Patient and Family Engagement in Hospital Quality and Safety. Content last reviewed June 2013. Agency for Healthcare Research and Quality, Rockville, MD.
<http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html>
2. Health Policy Brief: FEBRUARY 14, 2013 Patient Engagement
http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=86
3. Engaging Health Care Users: A Framework for Healthy Individuals and Communities,
<http://www.aha.org/research/cor/engaging/index.shtml>
4. Patient Safety Primer Last Updated: July 2016, The Role of the Patient in Safety
<https://psnet.ahrq.gov/primers/primer/17>
5. Guide to Patient and Family Engagement Exhibit 12. Involving Patients and Family Members at the Hospital Level <http://www.ahrq.gov/research/findings/final-reports/ptfamilyscan/ptfamilyex12.html>
6. The Joint Commission, Speak Up Initiatives <https://www.jointcommission.org/speakup.aspx>
7. Patient and Family Centered Care Partners www.pfccpartners.com

RESOURCE ARTICLES:

1. Health Research & Educational Trust. (2015, December). *Patient and Family Engagement Resource Compendium*. Chicago, IL: Health Research & Educational Trust. Accessed at www.hpoe.org, www.hpoe.org/pfecompendium Contact: hpoe@aha.org or (877) 243-0027

Executive Summary

By partnering with patients, their families and other caregivers, hospitals can improve the quality and safety of health care,^{1,2} reduce costs,³ increase employee satisfaction^{4,5} and improve the patient experience.⁶ Carmen et al.⁷ define patient and family engagement as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.” This definition acknowledges that PFE represents a continuum of strategies and interventions that can occur at the bedside, in the board room and in the community. Partnering with patients and families has many cascading benefits related to health care quality, patient activation and elimination of health care disparities. It can transform organizational culture in profound ways.

How to use this compendium:

The Health Research & Educational Trust (HRET) developed this resource compendium to help link PFE concepts and strategies to available resources. This compendium highlights the array of resources that can support hospital efforts to partner with patients and families and provides some recommendations on how the available resources can be used. The website addresses for each resource are hyperlinked from the title, and the titles in the table of contents are bookmarked within the document to ease navigation.

2. Transforming Patient-Centered Care: Development of the Evidence Informed Decision Making through Engagement Model Jennifer E. Moore, PhD, RN, Marita G. Titler, PhD, RN, FAAN, Lisa Kane Low, PhD, CNM, FACNM, Vanessa K. Dalton, MD, MPH, Carolyn M. Sampselle, PhD, RN, FAAN

Abstract

Background: In response to the passage of the Affordable Care Act in the United States, clinicians and researchers are critically evaluating methods to engage patients in implementing evidence-based care to improve health outcomes. However, most models on implementation only target clinicians or health systems as the adopters of evidence. Patients are largely ignored in these models. A new implementation model that captures the complex but important role of patients in the uptake of evidence may be a critical missing link.

Discussion: Through a process of theory evaluation and development, we explore patient-centered concepts (patient activation and shared decision making) within an implementation model by mapping qualitative data from an elective induction of labor study to assess the model’s ability to capture these key concepts. The process demonstrated that a new, patient-centered model for implementation is needed. In response, the Evidence Informed Decision Making through Engagement Model is presented. We conclude that, by fully integrating women into an implementation model, outcomes that are important to both the clinician and patient will improve.

Conclusions: In the interest of providing evidence-based care to women during pregnancy and childbirth, it is essential that care is patient centered. The inclusion of concepts discussed in this article has the potential to extend beyond maternity care and in fluence other clinical areas. Utilizing the newly developed Evidence Informed Decision Making through Engagement Model provides a framework for utilizing evidence and

translating it into practice while acknowledging the important role that women have in the process. Implementation of evidence-based practices is a central component of improving patient safety and quality of care. However, patient involvement in health care decisions has received little attention within implementation efforts. Most models or frameworks on implementation target clinicians or health systems as the adopters of evidence to improve quality of care (Graham & Logan, 2004; Kitson et al., 2008; Lomas, 1993; Stetler, 2001; Titler et al., 2001; Logan & Graham, 2010). Consumers of health care such as patients, families, and caregivers are largely ignored in these models. With the passage of the Affordable Care Act in the United States, increasing importance has been placed on the involvement of individuals taking an active role in their health care decision making. This is evident Sources of Funding: This project was funded by the National Institutes of Health Individual National Research Service Award, Grant #F31NR012855 (PI: Moore), and the Blue Cross Blue Shield Foundation of Michigan, Grant #1808. SAP (PI: Moore). Disclaimer: The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the U.S. Department of Health and Human Services or the Agency for Healthcare Research and Quality.

3. A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities, Jo Brett • Sophie Staniszewska • Carole Mockford • Sandra Herron-Marx • John Hughes • Colin Tysall • Rashida Suleman Published online: 18 July 2014 Patient (2014) 7:387–395 DOI 10.1007/s40271-014-0065-0 _ Springer International Publishing Switzerland 2014

Abstract

Objective Patient and public involvement (PPI) in research has expanded nationally and internationally over the last decade, and recently there has been significant attention given to understanding its impact on research. Less attention has been given to the impact of PPI on the people involved, yet it has been shown that the success of PPI in research can be reliant on the processes of engagement between these individuals and communities. This paper therefore critically explores the impact of PPI on service users, researchers and communities involved in health and social care research.

4. The impact of patient and public involvement on UK NHS health care: a systematic review, CAROLE MOCKFORD, SOPHIE STANISZEWSKA, FRANCES GRIFFITHS, AND SANDRA HERRON-MARX, International Journal for Quality in Health Care 2012; Volume 24, Number 1: pp. 28–38 10.1093/intqhc/mzr066

Abstract

Purpose. Patient and public involvement (PPI) has become an integral part of health care with its emphasis on including and empowering individuals and communities in the shaping of health and social care services. The aims of this study were to identify the impact of PPI on UK National Health Service (NHS) healthcare services and to identify the economic cost. It also examined how PPI is being defined, theorized and conceptualized, and how the impact of PPI is captured or measured. Data sources. Seventeen key online databases and websites were searched, e.g. Medline and the King's Fund.

Study selection. UK studies from 1997 to 2009 which included service user involvement in NHS healthcare services. Date extraction. Key themes were identified and a narrative analysis was undertaken. Results of data synthesis. The review indicates that PPI has a range of impacts on healthcare services. There is little evidence of any economic analysis of the costs involved. A key limitation of the PPI evidence base is the poor quality of reporting impact. Few studies define PPI, there is little theoretical underpinning or conceptualization reported, there is an absence of robust measurement of impact and descriptive evidence lacked detail.

Conclusion. There is a need for significant development of the PPI evidence base particularly around guidance for the reporting of user activity and impact. The evidence base needs to be significantly strengthened to ensure the full impact of involving service users in NHS healthcare services is fully understood.

5. Women's safety alerts in maternity care: is speaking up enough? Susanna Rance, Christine McCourt, Juliet Rayment, Nicola Mackintosh, Wendy Carter, Kylie Watson, Jane Sandall BMJ Quality & Safety Online First, published on 15 February 2013 as 10.1136/bmjqs-2012-001295

ABSTRACT

Patients' contributions to safety include speaking up about their perceptions of being at risk. Previous studies have found that dismissive responses from staff discouraged patients from speaking up. A Care Quality Commission investigation of a maternity service where serious incidents occurred found evidence that women had routinely been ignored and left alone in labour. Women using antenatal services hesitated to raise concerns that they felt staff might consider irrelevant. The Birthplace in England programme, which investigated the quality and safety of different places of birth for 'low-risk' women, included a qualitative organisational case study in four NHS Trusts. The authors collected documentary, observational and interview data from March to December 2010 including interviews with 58 postnatal women. A framework approach was combined with inductive analysis using NVivo8

software. Speaking up, defined as insistent and vehement communication when faced with failure by staff to listen and respond, was an unexpected finding mentioned in half the women's interviews. Fourteen women reported raising alerts about safety issues they felt to be urgent. The presence of a partner or relative was a facilitating factor for speaking up. Several women described distress and harm that ensued from staff failing to listen. Women are speaking up, but this is not enough: organisation-focused efforts are required to improve staff response. Further research is needed in maternity services and in acute and general healthcare on the effectiveness of safety promoting interventions, including real-time patient feedback, patient toolkits and patient activated rapid response calls.