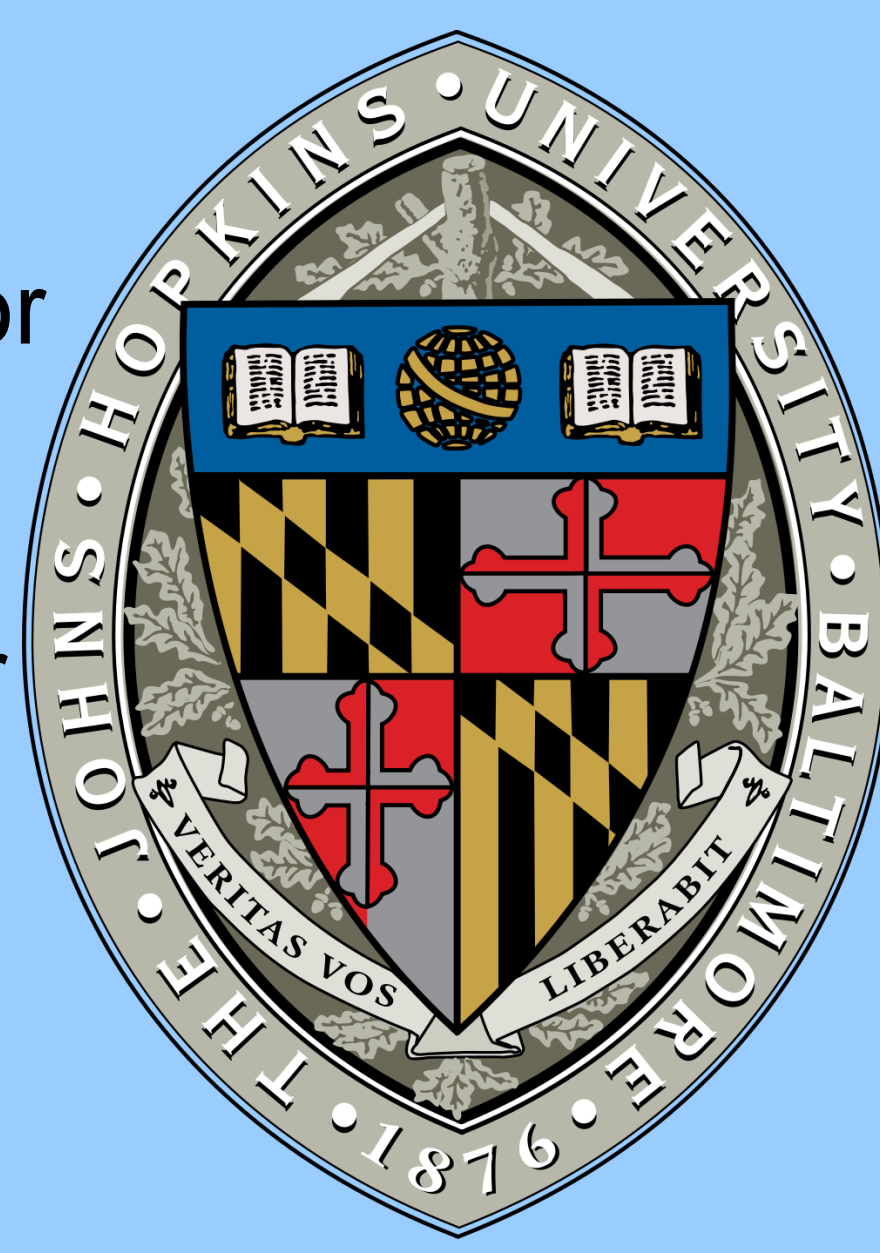


# “Engaging Patients and Families to Improve Care for Mechanically Ventilated Patients”

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## 1 Background

- Mechanical ventilation (MV) is associated with significant morbidity and mortality, including ventilator-associated pneumonia (VAP), and prolonged physical, cognitive and psychiatric dysfunction.<sup>1-3</sup>
- Successful completion of the proposed study will advance patient-centered outcomes research by generating new knowledge and improved care in the areas of critical care while partnering with patients/families to increase adherence with evidence-based recommendations and engaging them in the ICU setting

### Objectives of the Project:

- To partner with patients/families in all areas of research to improve care for mechanically ventilated patients.
- To use the data from focused group assessments to develop a “patient and family-centered ventilator toolkit” to improve provider communication regarding mechanical ventilation.
- To empower families to take an active role in the care of their mechanically ventilated loved one(s).

## 2 Methods

- Qualitative data are being gathered from structured interviews. The interviews focus on:
  - Patient/family experiences and perceptions of care practices surrounding MV.
  - Patient/family suggestions for improvements in care practices and communication during and after MV.
- Interview participants have been recruited using an opportunistic, snowball sampling strategy that targets patients and/or family members who have experienced MV in the recent past.
  - Structured interviews are being conducted both in person and using online video conferencing software. During the interviews patients are being asked if they noticed, were questioned, or were told about prevention strategies while in the ICU.
- The interviews are being digitally recorded and transcribed for analysis. Themes are being developed, expanded and collapsed in an iterative team-based manner based on grounded theory approach<sup>4</sup> to data collection and analysis. Presently, five themes have been identified:
  - Patient/family awareness of 5 evidenced-based strategies for preventing complications while on MV.
  - Patient/family reactions to variations to care.
  - Patient/family perceptions of involvement in care
  - Patient/family reactions over time to personal involvement while in the ICU
  - Patient/family suggestions for toolkit development

## 3 Results

The project is in its first stage of development. To date (October, 2016), we have recruited six participants, which has resulted in four focused group interviews. Our goal is to recruit a minimum of 24 participants.

Of the six patients addressed in our structured interviews (see Figure 1: Patient Demographics) five out of six patients received tracheotomies. One out of six patients was discharged on ventilation; and two out of six mechanically ventilated patients died.

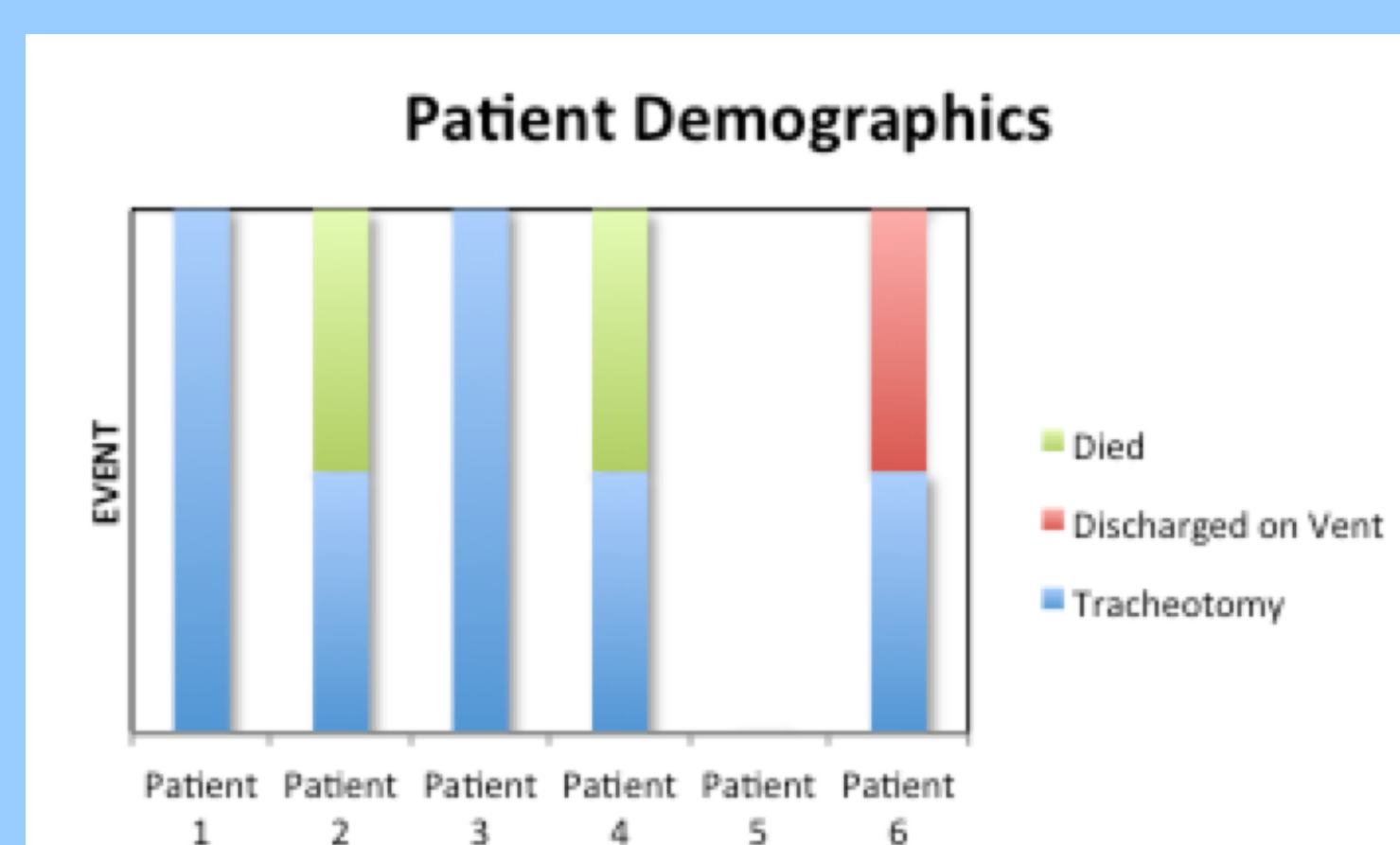


Figure 1. Patient Demographics

Data regarding patient/family awareness of strategies to prevent complications while on MV (Figure 2) show discrepancies in communication across the strategies. In all prevention strategy categories patients/families were less likely to ask or be told about an event than they were to notice an event taking place. Similarly, complications of delirium were the least communicated event by all participants. No patient/family member asked about spontaneous awakening trials taking place, which points to a lack of patient/family awareness of health care provider procedures.

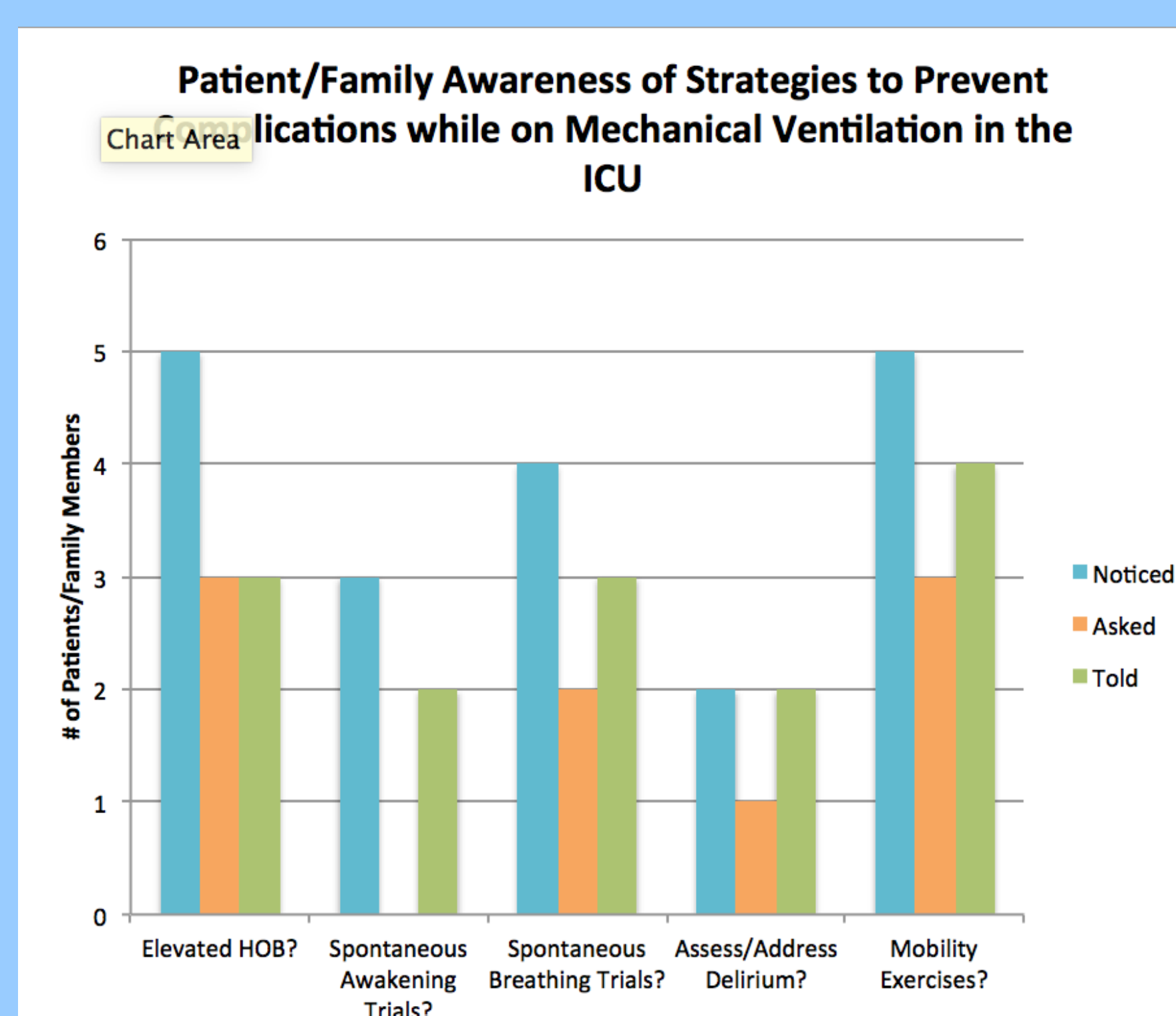


Figure 2. Patient/Family Awareness of Strategies to Prevent Complications while on Mechanical Ventilation in the ICU

## 4 Conclusions

Up to this point in the project, three preliminary findings on patient-centered care and outcomes has surfaced, and the following conclusions have been made:

- All participants emphasized the need for teaching/demonstration videos on prevention strategies and improved discharge information/medication reconciliation/provider contact information.
- Not all family members feel ready, able, or desire to be actively involved in the care of their loved one in the ICU.
- MV can be traumatic for the patient/family, and greater emphasis needs to be directed toward improved provider communication during the care of the mechanically ventilated patient to minimize stressors.

## 5 Future Directions

Our plan for Fall 2016 is to continue to recruit participants for the interviews by reaching out to PFAC leaders across the country. From analysis of the qualitative data, we will work with patients and families to develop a patient/family-centered toolkit to improve care of mechanically ventilated patients.

## 6 References

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