APPENDIX

Draft Interview guide for Patient and Family Engagement Study

CLINICIAN INTERVIEW GUIDE

Instructions to Begin Interview:

- 1. Introduce myself (whoever is present)
- 2. Describe objective of interview

The purpose of this study is to understand who, how, when and in what ways patients and their families may or may not be included in care in the ICU. As part of this project, we'd like to ask you some questions about caring for mechanically ventilated patients and interactions with these patients, and their families.

This interview will be audio-recorded so that we have an accurate record of your thoughts. If at any time you feel that the questions are too sensitive, I'm happy to turn off the tape recorder during that portion of the questioning. Once the interviews have been transcribed (typed out), we will destroy the tape recording. The transcript will contain no identifying information. At completion of the interview, we will provide a \$20 gift certificate as a small token of our appreciation.

Do you have any questions before we begin?

- 1. Establish rapport
 - a. Can you tell me a little bit about how long you have worked in this ICU? In your role?
- 2. We're interested in learning more about your interactions with MV patients and their families.
 - a. Can you tell me about a time when you cared for a mechanically ventilated patient and actively included the patient and his/her family in care?
 - i. Probes
 - 1. Can you describe how you included this patient and family in care?
 - 2. In what ways were the patient and family included?
 - 3. When did this occur during the patient's ICU stay?
 - 4. Were other clinicians involved in including this patient and family in care?
 - 5. Can you describe why you included this patient and family in care?
 - b. Can you tell me about a time about caring for a patient who was mechanically ventilated when you or your unit did **not** include the patient and/or family in care?
 - i. Probes
 - Can you describe why this patient or family was not included in care?
 - 2. How do you think your unit could have included the patient and his/her family more?
 - c. Please describe some conditions under which you would or would not include mechanically ventilated patients and their families in care
 - d. Can you tell me about any ways your ICU typically works with mechanically ventilated patients and families in care delivery?
 - i. Probes: are families invited to participate in daily care rounds? Is there space in the unit set aside for family-physician consultation? Do families assist when their loved one is delirious in the ICU?
- 3. Generally speaking, are there common situations when patients and families are included in care?
 - a. Common instances when patients and families are **not** included?
- 4. Factors in the ICU environment that may serve as barriers or facilitators to engagement?

APPENDIX

FAMILY INTERVIEW GUIDE

Instructions to Begin Interview:

- 1. Introduce myself (whoever is present)
- 2. Describe objective of interview

The purpose of this study is to understand who, how, when and in what ways patients and their families may or may not be included in care in the ICU. As part of this project, we'd like to ask you some questions about your recent experience in the ICU and how the ICU team interacted with you and your family, when caring for your loved one.

None of the information you provide here will be available to the ICU team that is currently caring for your loved one or cared for your loved one. This interview will be audio-recorded so that we have an accurate record of your thoughts. If at any time you feel that the questions are too sensitive, I'm happy to turn off the tape recorder during that portion of the questioning. Once the interviews have been transcribed (typed out), we will destroy the tape recording. The transcript will contain no identifying information and no ICU clinician will know what we discussed. At completion of the interview, we will provide a \$20 gift certificate as a small token of our appreciation.

Do you have any questions before we begin?

- 1. Establish rapport
 - a. Can you tell me a little bit about your family and your loved one?
 - i. How long has your loved one been in the ICU?
 - ii. Can you describe how you feel about the care your loved one's received?
- We are interested in learning more about the interactions you've had with ICU clinicians and if and how you were included in your loved one's care. By clinicians, I mean the nurses, doctors, physical therapists, nurses aides and any other ICU staff member who took care of your loved one.
 - a. Can you tell me about an instance when you felt that the ICU clinicians included you and your family in care?
 - i. Probes:
 - 1. Who (which clinicians) involved you in care?
 - 2. How and in what ways did they involve in you care?
 - 3. When did this occur during your loved one's stay?
 - b. Can you describe a situation during your loved one's hospitalizations when you feel that you were **not** included in care?
 - i. Did you want to be included in this part of care but was not invited to?
- 3. If money or time were no option, can you explain how you would like to be included in your loved one's care, if at all? In the ideal situation, what would that look like?
 - i. Probes
 - 1. Certain clinicians important to this?
 - 2. Timing would it depend on your loved one's ICU stay?
 - 3. Certain parts of care that you'd most like to be a part of?
 - 4. Care processes that you would **not** want to be a part of?
- 4. Can you tell me if there are certain things in the ICU environment that may serve as barriers or facilitators to you or your loved one's engagement in care?