

# Best Practices Toolkit for Family Participation in ICU Rounds

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## Abstract

**Rationale, Aims and Objectives:** Guidelines recommend inviting family members of intensive care unit (ICU) patients to rounds. We aimed to create a toolkit to support family participation in ICU bedside rounds, based upon evidence from research and in collaboration with ICU family member representatives and healthcare providers. **Methods:** A multi-method qualitative research program was conducted to provide an evidence-base. Ethnographic observations of rounds and interviews and focus groups with family members and ICU healthcare providers were analyzed for key themes, barriers and facilitators of participation, and suggestions. A full day workshop with family representatives and providers (physicians, nurses, social workers, and unit managers) from a diverse range of adult ICUs in Western Canada, including several community ICUs and a majority of large, urban ICUs enabled the collaborative development of key toolkit elements. **Results:** We have developed an evidence-informed approach to patient-and-family-centered rounds that highlights the importance of 6 key elements foundational to patient and family centered rounds: Invitation, Orientation, Engagement, Summary, Questions, and Communication Follow-Up. We describe strategies, techniques, and templates to optimize these elements and interactions so that communication is more meaningful, and to facilitate the ability of family members to adopt a meaningful role as contributing members of the care team. **Conclusion:** There is consensus on general strategies for facilitating family participation in rounds and meaningful communication between family and the healthcare team during rounds as an important element of the continuum of communication in the ICU. The incorporation of these elements should be standardized, though tailored to user needs.

## Introduction

Current guidelines recommend inviting family to attend ICU bedside rounds as one way of improving communication and increasing satisfaction<sup>1</sup>. There is little guidance as to how participation can be optimized so that family members feel valued as team members and the vulnerabilities of having a critically ill loved one are respected while maintaining the efficiency and high quality of rounds<sup>2-4</sup>. Recent literature has used the term ‘family centered rounds’ when traditional multidisciplinary rounds are adapted to provide family with an invitation to attend, a summary of information discussed, and an opportunity to ask questions<sup>5,6</sup>. Such an approach has not consistently demonstrated an improvement in family satisfaction with communication or shared decision-making<sup>7,8</sup>. Family and providers have differential awareness of roles family may adopt during rounds; more explicit orientation and engagement strategies may help clarify this<sup>4</sup>.

We aimed to develop a framework for patient and family centered rounds by defining key structures, processes, facilitators and barriers to optimal family participation, and tools to maximize and mitigate these factors, respectively. Our program of research has included multicenter multi-city ethnographic observations, interviews and focus groups, and a one-day workshop for toolkit development<sup>4,9</sup>. In this manuscript we report the development of a guide on how to conduct patient and family centered rounds in a way that balances the needs of both family members and providers.

## Methods

The toolkit we present here is informed by a large program of research, some of which has been reported elsewhere<sup>9,10</sup>, and some which we report here for the first time.

*Ethnographic study:* Our research program began with an observational study of family participation in ICU care team rounds<sup>10</sup>. We conducted ethnographic observations of rounds, employing both structured (documentation of pre-specified processes) and unstructured (note-taking to characterize interactions and context) data collection techniques to directly observe and describe family member attendance in ICU rounds in seven medical-surgical ICUs located in seven hospitals in three Canadian cities in the province of Alberta.

*Interviews and focus groups:* Interviews and focus groups with family and healthcare providers were conducted in four urban tertiary care medical-surgical ICUs within a large city, and in five additional ICUs across Alberta, one of which was an urban tertiary care centre and the others which serve a rural patient population<sup>9</sup>. These in-depth interviews and focus groups explored facilitators, barriers, and suggestions for improvement from the perspectives of participants in ICU family rounds. Our research program culminated in a full-day toolkit development workshop.

*Workshop:* A diverse group of family members and healthcare providers from 14 adult ICUs were invited to attend a one-day, 8-hour workshop to deliberate upon and collaboratively develop a toolkit to guide patient and family centered rounds. The key facilitators identified through our qualitative observations and interviews<sup>9,10</sup> were incorporated into an electronic survey with a 5-point Likert scale for rating the importance of each facilitator, along with 2 open-ended questions for respondents to write additional facilitators and site-specific contextual factors (see Appendix 1). The survey was distributed to family members and providers one week before the workshop to identify the highest priority elements of patient- and family-centered rounds. Family members and providers were provided with a summary of key findings from the research to date, and were asked to come to the workshop prepared to discuss ideas on how key processes involved in patient- and family-centered rounds could be developed into a practical toolkit for use in the clinical setting.

The workshop was held on November 5<sup>th</sup>, 2018 and divided into morning and afternoon sessions. The day commenced with a review of existing literature, findings from previous research, and objectives for the workshop, which were to 1) consolidate components of the toolkit including structures, processes, and existing tools, 2) refine toolkit components to optimize communication with all stakeholders, and 3) prioritize further tool development. Participants were divided into six groups. Groups rotated through 12 stations representing structures, processes and tools to guide implementation of the 6 highest priority elements of patient- and family-centered rounds identified in the pre-workshop survey. Groups were asked to generate ideas on the structures, processes and tools, and vote on the importance and relevance of the tools. At the end of the morning and afternoon sessions, large group discussions were held to review and discuss the ideas generated at each workshop station and establish consensus on which elements to include in the final toolkit.

The collaborative worksheets from each activity station were retained for subsequent analysis and to support toolkit development. Three research team members independently took memos during the group discussion portions of the workshop, which were also audio-recorded and transcribed verbatim. The three sets of notes were compiled and collated to create a record of the discussions; the researchers reviewed the collated notes and transcripts for fidelity. From the notes and transcripts, the researchers assembled a consensus list of toolkit items that had been agreed upon and discussed by workshop participants, including numerous suggestions and examples of their application. This consensus list formed the basis for the final toolkit components reported below.

## Results

Out of 55 individuals invited a total of 23 participants attended the toolkit development workshop, including ICU physicians (n=4), nurses (n=5), unit managers (n=8), family member representatives and advisors (n=6), one social worker, and one spiritual care practitioner. Three participants were from rural sites, while the majority of attendees (n=20) were from large urban community or academic hospitals.

Seventeen participants completed the pre-workshop survey, fourteen of whom self-identified as healthcare providers and three who self-identified family members (see Appendix 1). Based on our ethnographic data, interviews and focus groups, and the pre-workshop survey, we identified six elements foundational to patient and family centered rounds: Invitation, Orientation, Engagement, Summary, Questions, and Communication Follow-Up (Figure 1). For each element, the structures and processes that promote communication, relationship-building, and shared decision-making identified in the workshop and the associated tools to support these practices are described below. Tools include standardized unit practices, key talking points, education aids, mnemonics, written templates and local champions, and are summarized in the Supplemental Material as a complete guide. Select tools and quotations are illustrated in Table 1.

## Invitation

1. *Healthcare providers inviting family members to rounds* Workshop participants recommended educating staff that inviting families to rounds is the standard of care and part of unit culture. Any member of the care team can encourage family attendance, and multiple invitations are beneficial.
2. *When and where to invite family members to rounds* Participants suggested inviting family as soon as is practical (e.g., at first contact with family, and if possible in the presence of a patient who is awake and aware), with reminders throughout the patient's ICU stay.
3. *Who to invite to rounds* Participants indicated it is ideal to ask the patient who they would like to participate in rounds. For patients who are unconscious or unable to make decisions, participants suggested asking the surrogate decision maker to select an attendee. Participants considered an appropriate rounds attendee to be someone the patient would likely agree to have present, who could reflect the patient's voice, and who feels reasonably comfortable participating. For large extended families, participants suggested that a single family spokesperson could attend rounds and relay information to the larger family unit.
4. *Supporting materials for families invited to rounds* To promote consistent messaging, participants suggested providing staff with standard information on how to invite family members to rounds. Recommended tools included pamphlets, invitation cards, and posters to accompany verbal invitations and aid family members' understanding and recall. Participants indicated written materials would ideally be simple, concise, identify the structure and purpose of rounds, and include illustrative pictures and graphics. Posters in waiting areas were suggested as a passive means to raise awareness of rounds, as well as index-sized invitation cards which could include a personal invitation from a staff member.

## Orientation

*Distinguishing orientation from invitation* Participants considered 'invitation' as presenting rounds as an opportunity for family members to communicate with providers (i.e., 'getting them there'). 'Orientation' then involves introducing the family member to the team, describing the structure of rounds, and outlining the role of family in rounds (i.e., 'why they are there').

2) *Ideal healthcare providers to orient family members to rounds* Participants discussed two main factors to assess which healthcare provider is most appropriate to orient family to rounds: (a) who is present when family is visiting, and (b) who has the most consistent presence at the bedside. This will most likely be the bedside nurse, although participants noted any healthcare provider can assume this role. Participants indicated that a standardized orientation would provide consistency. Information about rounds can also be placed in a welcome package or on a whiteboard in the patient's room.

### 3) *When to begin the orientation conversation*

Participants thought orientation would ideally happen as close as possible to ICU admission, although our data emphasizes that family are often initially overwhelmed and have difficulty processing information early

in a patient's stay. An orientation within 24 hours or prior to the first rounds following patient admission was deemed appropriate for most cases. Participants noted that the orientation might need to be repeated when additional family members arrive and that it may be helpful to provide family with a brief orientation every time they join rounds to reinforce key points.

#### 4) *Where to hold the orientation conversation*

The patient's bedside was identified as an optimal location for orienting families to rounds, as this is where rounds ideally occur. Conversations inside the room provide an increased sense of respect and afford opportunities to involve the patient when possible.

#### 5) *Providing standardized "coaching" for family immediately before rounds*

Participants suggested coaching might involve consistent messages about the purpose of rounds, and prompting family on how to optimally participate (e.g., advocating for the patient, asking questions, requesting clarification). Family can be encouraged to write down their questions in advance so they remember what they want to ask during rounds.

#### 6) *Ground rules to pre-empt and manage challenging scenarios*

Participants suggested ground rules include an expectation of respectful conduct, a designated time during rounds for family input, and opportunities for more in-depth conversations after rounds. Healthcare provider education could teach approaches to addressing disruptions and diffusing conflict. Participants suggested a social worker participate in rounds when disruptions or conflict is anticipated.

IDEA, acronym for introductions, definition, encouragement, and alternatives, is one tool we described to encompass important discussion points within an orientation. (Supplemental material)

## Active Engagement

1. *Identifying how family members can contribute to patient care* In addition to supplementing medical information, family members were considered as valuable resources for types of patient information often not available in charts, including: baseline routine, function, and values.
2. *Identifying roles or active tasks that family can perform as members of the care team* Participants identified potential family roles as: providing health information, directed information gathering, patient advocacy, patient support/comfort, physical care (e.g., delirium identification, mobilization assistance), and communication liaison (e.g., updating other family members, continuity of care between providers). Participants emphasized that family members will differ in which roles and tasks, if any, they wish to participate in; case-by-case assessment of family preferences will be needed. Family members could then be coached within their preferred roles and the roles adapted as needed.

Table 2 describes a written template developed as a framework for family member use during rounds as a mechanism of guided participation and note-taking. This framework increases role clarity by giving family members an idea of how they can offer patient-related information.

## Summary of Rounds

### *Determining the most important information to summarize for family*

Family members and providers described important components of a patient- and family-oriented summary: big picture issues, progress of patient status, plan (daily and long-term), prognosis, priorities and potential problems, with the first three being most critical (5 P's mnemonic tool in Supplemental material).

*Determining when to provide the summary (e.g., at end of rounds, before or after family questions)* Participants indicated that a single summary at the end of rounds is more efficient than summarizing each issue as it is discussed. They suggested the summary be provided before eliciting family questions, as common questions may be answered in the summary. When family is not available during rounds, the summary can be provided when they next arrive or can be communicated by telephone.

## Opportunity for Questions

1. *Encouraging different types of family input* Participants suggested encouraging family to think of questions, comments, and concerns ahead of time and write them down. Participants indicated it was particularly important that the rounding team invite questions and concerns, acknowledge and validate family input, and listen attentively when family is speaking. Formulating questions into open-ended format can increase the sense of welcome and promote dialogue (Examples within Supplemental material.)
2. *Crafting optimal responses to family questions and input* Families emphasized that questions are best answered with straightforward language, and in a respectful and empathetic manner. Body language and tone were highlighted as essential for building trust and establishing rapport. When there are many questions, or it is not the right time or place for discussion (e.g., a private setting is needed), participants suggested validating the question/concern and setting a time to address the issue after rounds (e.g., in a formal meeting).

## Communication Follow-Up

1. *Best ways to communicate with families outside of rounds* Participants highlighted that communication can occur informally throughout the day. Any healthcare provider was considered appropriate to communicate with family, as long as information is consistent across providers. Phone calls were identified as an alternative way to communicate with family. Whiteboards were recommended, although participants emphasized that information on a whiteboard must respect patient confidentiality.
2. *Family follow-up after rounds*

Participants suggested that a designated member of the healthcare team check in with family and ensure their questions have been addressed after rounds has concluded. A large number of questions may suggest the need for a separate family meeting. Family could also be encouraged to write down questions that occur to them before the next rounds.

1. *Accommodating families unable to physically attend rounds* Participants felt family should be asked their preferences for alternate communication early in the patient's stay. Options suggested included telephone or videoconferencing. However, family access to computers and internet cannot be assumed. For families who visit outside of rounds, verbal summaries by a healthcare provider who was present during rounds was suggested as an alternative.
2. *Supporting vulnerable families* Participants recognized that family characteristics and circumstances (e.g., language barrier, minority groups, elderly/frail, complex family relations, social stigma) may result in vulnerability. Participants emphasized that all family members are vulnerable in some way and recommended asking all families how they are coping and what support and resources would be of benefit to them. **Discussion** Professional organizations have advocated for family member participation during ICU bedside rounds for nearly 20 years<sup>1,11-13</sup>. Recent North American data indicates increases in family presence with the adoption of open visitation policies, however this speaks little to the nature of family participation<sup>14-16</sup>. By partnering with both family members and providers, we have developed an evidence-informed approach to patient and family centered rounds that highlights the importance of six key elements foundational to patient and family centered rounds: Invitation, Orientation, Active

Engagement, Summary, Opportunity for Questions, and Communication Follow-Up, and we describe strategies to optimize these elements and interactions so that communication is more meaningful.

Rationale for toolkit approach: There is broad support for the notion of involving patients (and by extension, family members who serve as patient representatives when the patient lacks capacity) in ICU rounds, as a daily opportunity for shared decision-making with a multidisciplinary team<sup>1</sup>. Defining the elements of this participation has remained much more elusive. Family engagement can be anywhere in a passive–active spectrum (e.g., presence versus making suggestions) while decision-making approaches vary from paternalistic to patient-informed<sup>2,17,18</sup>. Given the dynamic and complex nature of ICU care and rounds, family members may adopt variable types of engagement and decision-making throughout the course of rounds. This anticipated variability in the nature of family participation does not preclude defining crucial elements central to PFCC rounds and robust communication practice however. Considering rounds is a discrete clinical encounter, similar to insertion of a central line or surgery, it should be amenable to a simple tool like a checklist to standardize processes<sup>19,20</sup>. Recognizing that checklists cannot replace clinical judgment or appropriate responses to emotion, our research has identified six key structures and processes for PFCC rounds along with tools to support fluidity and responsiveness to the needs of patients, families, and team members. Previous studies involving family participation in adult ICU rounds share the common processes of invitation, summary, and opportunity for questions; however, adopting these elements alone risks constraining family members to more passive roles; elements that promote active engagement are notably absent from these prior recommendations<sup>5,7,8,21</sup>. To our knowledge, our tool for active engagement is the first approach described for coaching family members on participating in rounds in a way that recognizes them as active members of the care team.

Adoption of tools: Within a range of possible family roles in rounds, our family member participants have stressed that they adopt the various potential roles in different ways, and that the care team must be flexible and explore how families prefer to be engaged. Our toolkit was developed by family members and providers from a myriad of practice settings, and all emphasized that components will need to be tailored to local needs and context, ideally within a quality improvement paradigm. Furthermore, the toolkit elements may be difficult to introduce all at once; individual units can determine both the sequence and number of elements to implement within a given timeframe. For some centers, implementation of these structures and processes may also require a cultural shift. Education about the rationale for toolkit elements and addressing concerns will be essential for provider engagement.

Strengths of this study include a multi-method approach involving a provincial network of stakeholders from varied practice settings, and a rich description of practical tools and how they can be implemented. Limitations include situating the study within a provincial practice network in Western Canada that largely functions with open family visitation hours, potentially limiting transferability to other contexts. We have also focused mostly on practices to support family as opposed to patients. This does not understate the importance we place on patient involvement whenever possible. Finally, we present suggestions for patient and family centered rounds and acknowledge that further research to determine the impact of implementation is needed.

## Conclusion

Based on the perspectives and ideas drawn from family members of ICU patients and ICU healthcare providers, we have developed a practical approach to facilitate active family member participation in ICU bedside rounds. Our study highlights the importance of 6 elements in supporting the participation of family members in rounds: Invitation, Orientation, Engagement, Summary, Questions, and Follow Up. Specific strategies for facilitating meaningful communication between family and the healthcare team during rounds situate rounds as an important element in the continuum of communication in the ICU. Next steps will involve implementing, evaluating, and adapting the toolkit within local contexts.

## Abbreviations

ICU: intensive care unit

PFCC: patient and family centered care

*Declaration*

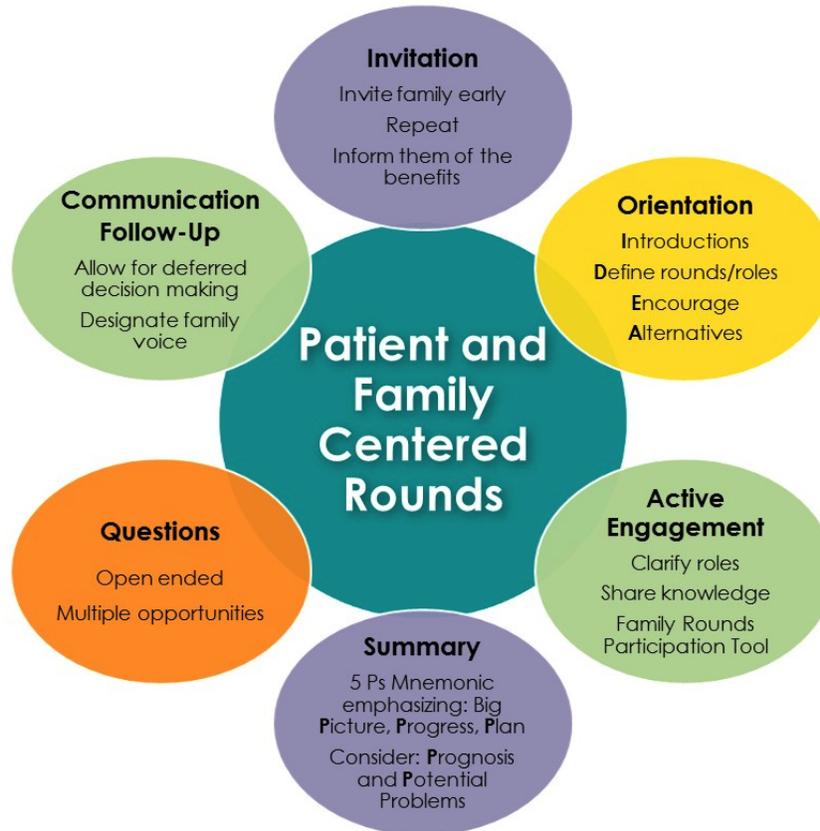
Ethical Approval and Consent to participate: Ethical approval for Phases I and II was attained under REB15-1891. Phase III was conducted as a quality improvement project as per ARECCI guidelines and as set forth in the Helsinki Declaration.

Authors' contributions: Each of the study authors has made significant contributions to the manuscript. Selena Au, Amanda Roze des Ordon, and Tom Stelfox are critical care physicians with the University of Calgary and were all responsible for study conception, protocol design, and data interpretation. Kenneth Blades is a qualitative researcher with the University of Calgary's Ward of the 21st Century Research & Innovation Centre with an MA in sociology, and contributed to methodological design, data collection, data analysis, and manuscript preparation. Selena Au, Amanda Roze des Ordon, and Kenneth Blades analyzed and coded qualitative interview and focus group data. All authors were responsible for iterative manuscript writing, critical review for intellectual content and have approved the final version to be published.

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**Figure 1.** Key structures and processes foundational to patient and family centered rounds are summarized as a toolkit with 6 key practices.

## Patient and Family-Centered ICU Rounds Toolkit for 6 Key Practices



**Table 1.** Examples of Family and Provider Developed Tools to support 6 Key Elements of PFCC Rounds

6 Key Elements of PFCC Rounds	Patients & Families Practices	Providers Practices
<b>Invitation</b>	Patients and families are invited to join daily rounds to discuss patient care plans. If you can't make it, let us know other ways and times for communication.	"We are starting rounds shortly. We will be reviewing why Joe is in the ICU and talk about a plan for his care as a team. Would you like to join in?"
<b>Orientation</b>	Please let us know what you like to be called and your relationship to the patient, and how you are involved in your loved one's care.	Before/at the start of rounds: <b>I</b> – Introductions/Invitation <b>D</b> – Definition <b>E</b> – Encouragement <b>A</b> – Alternatives

6 Key Elements of PFCC Rounds	Patients & Families Practices	Providers Practices
<b>Active Engagement</b>	Utilize the <b>Family Note-Taking/Rounds Participation Tool</b> to help organize your questions and thoughts prior to rounds	“Are there other things you want us to know about how Joe’s doing?” “What do you think Joe would think?”
<b>Summary</b>	We should provide in summary: <b>Big Picture:</b> “What are the main concerns today?” <b>Progress:</b> “Is today better, the same or worse?” <b>Plan:</b> “What is the plan for today?” “What things will be changed? Why?”	5 Ps Mnemonic: <b>B</b> ig <b>P</b> icture, <b>P</b> rogress, <b>P</b> lan, <b>C</b> onsider: <b>P</b> rognosis <b>P</b> otential Problems
<b>Questions</b>	“Can you explain to me what you meant by SBT?” “When do you expect him to get the breathing tube out?” “How common is this kind of confusion?”	“Was there anything that you didn’t hear or understand that you’d like to talk about later?”
<b>Communication Follow-Up</b>	“I think I understand but our daughter should be here before we make any decisions. Can we schedule a meeting later?”	“I’ll have a better idea of the treatment options after I talk to your oncologist/ review Joe’s chart... can we schedule a meeting later?”

**Table 2.** Family Rounds Participation Tool to Support Active Engagement. This template coaches family on how they can help the healthcare team best care for their loved one.

**Active Engagement** Learning from family about the patient and respecting their wishes to help

**Family Rounds Participation Tool:** As someone who knows the patient well, please reflect and give information to the **About the Patient** Please help us get to know your loved one. This will help direct the team’s care plan.  
**Take Home Message** The team should provide a summary for you after rounds. If this is missed, please ask for one!  
**Opportunity for Questions** You can always pass on questions for one of the team to ask on your behalf.

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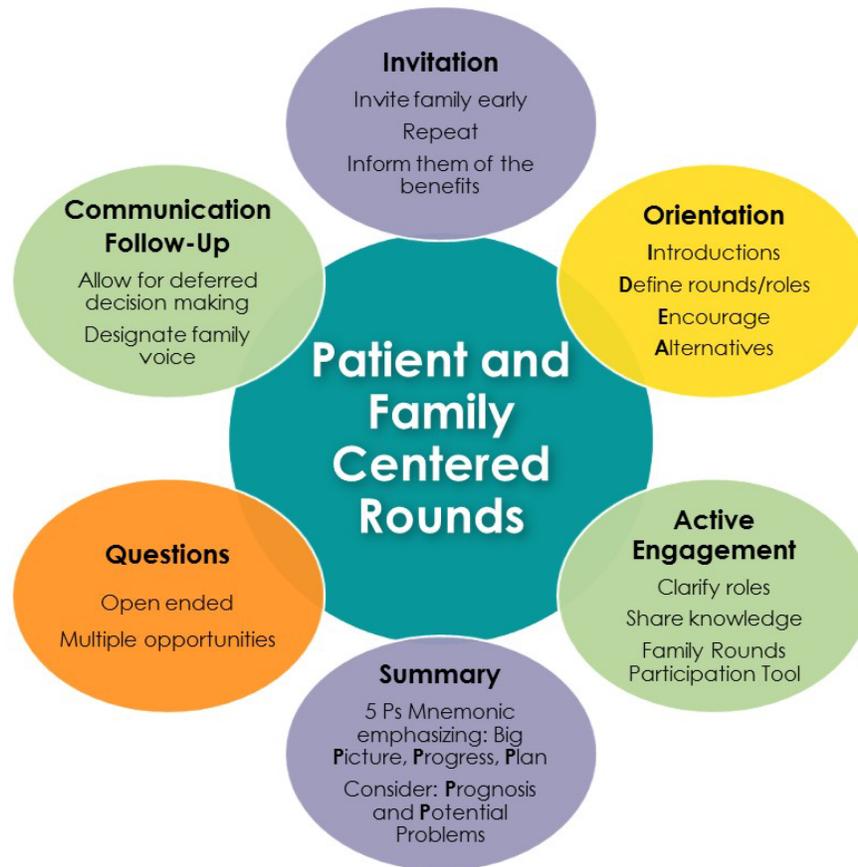
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## Hosted file

Toolkit Table 1 - Examples.docx available at <https://authorea.com/users/313473/articles/443959-best-practices-toolkit-for-family-participation-in-icu-rounds>

## Hosted file

Toolkit Table 2 - Active Engagement Tool.docx available at <https://authorea.com/users/313473/articles/443959-best-practices-toolkit-for-family-participation-in-icu-rounds>