

**INITIAL CONTACT**

Hello, my name is \_\_\_\_\_, and I am a \_\_\_\_\_ [patient advisor and researcher] in the Department of Critical Care Medicine at the University of Calgary. Is it okay if I talk to you for a few minutes to see if you are interested in participating in a research study about testing a new process to communicate information with patients and families before they transition out of the ICU?

<p><i>If agrees to hear more</i></p> <p>↓</p> <p>CONTINUE</p> <p>↓</p>	<p><i>If does not agree to hear more</i></p> <p>↓</p> <p><i>Thank you for your time. [Record on recruitment sheet]</i></p>
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**PURPOSE OF THE STUDY?**

- Currently in Calgary adult ICUs there is no standard process to include patients and families in planning their transition out of the ICU to another unit or to home. The goal of this study is to pilot test a new process of communicating information to patients and families. This new process involves providing:
  - 1) A written ICU summary that describes what happened to [you/patient's name] in the ICU and what [you/patient's name] might experience or expect after ICU; and
  - 2) A one-on-one conversation with a member of [your/patient's name] healthcare team to review and discuss the transition summary
- By increasing the involvement of patients and families in preparing for ICU transition, we hope to help patients and families will feel more informed and less anxious about what to expect when they leave ICU as well as feel better prepared to manage next steps in their healthcare.
- This small pilot study will help inform the need for a larger study and potential policies and procedures for engaging patients and families in ICU transitions in care.

**WHAT WOULD I HAVE TO DO?**

If you volunteer to participate in this study, you **MAY** be asked to do two things:

1. **Receive and discuss with a member of [your] ICU care team details included in a written ICU summary.** Summary will focus what happened to you in the ICU and what you might expect after leaving the ICU. During this one-on-one time, [you] and the clinician (nurse, nurse practitioner) will talk about [your] condition in ICU, where [you] will be transitioning to, and any follow-up care instructions or resources. [You] may be asked to repeat back what was discussed to ensure the clinician explained things clearly and that all [your] questions were answered. **\*\* Not all study participants may participate in the transition summary depending on the availability of a clinician who is part of the study.**
2. **Complete a short questionnaire** with a member our research team approximately one week after [your] transition out of the ICU. The researcher will follow up with you by telephone if you have been discharged from the hospital or in the hospital unit that [you] transition to from the ICU. The questionnaire will take about 10 to 15 minutes to complete. **ALL STUDY PARTICIPANTS WILL BE ASKED TO COMPLETE THE QUESTIONNAIRE, WHETHER THEY COMPLETED THE TRANSITION BUNDLE OR NOT.**
3. We also will **want to access [your] electronic medical record** only to find out if you visited the hospital emergency department or were readmitted to the hospital within a month of transitioning out of the ICU

## WHAT ARE THE RISKS/BENEFITS IN PARTICIPATING?

There are no risks to being in the study. Some people may find answering questions or participating in the review and discussion of the information in the transition summary tedious or tiring. Breaks will be offered as needed. You can decline to answer any questions or discontinue participation at any point.

We hope that the transition bundle will help inform you about [your/patient's name] medical condition and steps after ICU, but this cannot be guaranteed. The information learned from this study will help inform how we may be able to positively engage future **patients and families** in the transition process from ICU.

## DO I HAVE TO PARTICIPATE? /WILL MY RECORDS BE KEPT PRIVATE?

If you choose to participate in this study all the information you provide is strictly confidential. Study results will be presented as grouped data, with no identifying or personal information. I would like to assure you that this study has been reviewed and received approval by the University of Calgary Ethics Board and Alberta Health Services Research Administration.

The final decision about participation is yours. Your decision to take part in this study is voluntary. You may refuse to participate, or you may withdraw from the study at any time. **Your decision regarding your participation will NOT affect you/your family member's care at this hospital.**

**After hearing about the study, what questions can I answer for you?**

**Would you like to participate?**

If yes,	If no,
<i>We appreciate your interest and look forward to having you in the study.</i> <b>Continue with informed consent process</b>	<i>Thank you for listening. May I ask why you do not want to participate?</i> <i>[Record in recruitment log]</i>

## **Informed Consent Process**

I provided you with the main information that is in the informed consent form. However, it is very important that you read through the consent form and that you understand what it says. I am happy to answer any questions that you have after reading the detail.

- I will give you time to think about what we discussed, read over the consent form and think of questions you might want to ask me. **Would 15 minutes be enough time?**
- Review and sign informed consent
- Have bedside nurse witness the consent
- Provide copy of signed consent to participant for their files
- Patient's consenting to participate, include a copy in their chart (red binder) back of legal section.

## **BACKGROUND INFORMATION FOR THE PATIENT RECRUITER**

- Transitions in care describe a patient's movement from one care setting or location to another, such as from an operating room to an ICU, or an ICU to a medical unit, or from the hospital to home.
- Transitions can be difficult for patients and families, but transitions from the ICU can be particularly challenging as patients and families must adapt to a new healthcare team, different daily routines, no longer one-to-one nursing care; all of which can be stressful and overwhelming. As patients may still be very sick when they leave the ICU and struggling to make sense of what they may or may not remember about their ICU experience, the transition can be even more traumatic.
- There are currently no standard procedures in Calgary ICUs for involving patients and their families in the transition process, yet research suggests that engaging patients and families in transition conversations and providing written information can help reduce anxieties during the transition period and help better prepare them in managing their next steps in recovery.
- I understand that this is a difficult time for your family, but your participation could make things easier for future families by what we learn from this study.
- I am not part of your family member's treating team and cannot answer questions about your family member's treatment.
- Foothills Hospital is a teaching hospital involved in research including the research that I am a part of that focuses on improving transitions out of ICU.

**PATIENT TRANSITIONS IN CARE (TIC) SUMMARY ICU  
PROVIDER PROCESS FEEDBACK FORM**

1. What is your professional role?  
 Nurse Practitioner       Nurse Clinician       Bedside Nurse
  
2. What was your role in completing and delivering transitions in care summary?  
 Completed & delivered       Completed only       Delivered only
  
3. If you delivered the TIC summary, with whom did you interact?  
 Patient & family       Patient only       Family only

Please provide feedback on a Transition in Care summary that you recently completed.

	Yes	No	Comments
4. Was the time you spent preparing the TIC summary reasonable within your work demands?	<input type="checkbox"/>	<input type="checkbox"/>	
5. Were you interrupted to perform other tasks while you were preparing the summary?	<input type="checkbox"/>	<input type="checkbox"/>	
6. Was it clear how you should complete the TIC summary?	<input type="checkbox"/>	<input type="checkbox"/>	
7. Did you have all the information you needed to complete the summary?	<input type="checkbox"/>	<input type="checkbox"/>	
8. Were you able to use a teach-back method to deliver the information to patient/families?	<input type="checkbox"/>	<input type="checkbox"/>	

9. Approximately how long did you spend preparing the TIC summary? \_\_\_\_\_ minutes
  
10. Approximately how long did you spend with your patient/family delivering and discussing the information in the TIC summary? \_\_\_\_\_ minutes
  
11. Please provide any feedback that about your experience completing and delivering the TIC summary. (what worked well, what didn't work well, any recommendations)

## Participant Follow-Up Questionnaires

Participants were followed-up within a week of their transition from the ICU to complete a questionnaire. The questionnaire was administered by ICU-B2H patient partners.

### PATIENT/CAREGIVER EXPERIENCE of ICU TRANSITIONS

1. **How long has it been since you [the patient's name] transitioned from the ICU?**
  - Within a week
  - More than a week but less than a month
  - More than a month but less than 3 months
  - More than 3 months
  
2. **BEFORE leaving the ICU, did you have a conversation with a member of your [the] team to discuss your [the patient's name] ICU stay and what your next steps might be?**
  - Yes
  - No
  - Unsure
  
3. **BEFORE leaving the ICU, did you get information in writing summarizing your [the patient's name] ICU stay and what your [the] next steps might be?**
  - Yes
  - No
  - Unsure

4. **BEFORE leaving the ICU, how would you rate your understanding about:**

	1	2	3	4	5
	Poor	Fair	Good	Very Good	Excellent
Your [the patient's name] medical condition that brought you to the ICU					
Events that happened while you [the patient's name] were in the ICU					
How your [the patient's name] ICU stay might affect your [the patient's name] physical and psychological health (short and long-term impact)					

**ICU to WARD TRANSITIONS ONLY**

5a **BEFORE leaving the ICU, how would you rate your understanding about:**

	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
What to expect about your [the patient's name] care on the hospital ward (e.g., nurse-to-patient ratio, number of patients per room, differences from ICU)					

Were you aware of the following information about the unit you [the patient's name] were [was] transitioning to:

- Unit name/medical service       Yes                       No                       Unsure
- Unit number                               Yes                       No                       Unsure
- Unit contact number                       Yes                       No                       Unsure
- Name of your doctor                       Yes                       No                       Unsure

**ICU to HOME TRANSITIONS ONLY**

5b BEFORE leaving the ICU, how would you rate your understanding about:

	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
Your [the patient's name] prescribed medications and possible supplements – when to take them and why					
Follow-up appointments and tests that you [the patient's name] need to make or appointments made for you [the patient's name] before leaving the ICU – what appointments, when and where					
Changes to your [the patient's name] diet as a result of your medical condition					
Changes to daily routine (walking, driving, working) – what you [the patient's name] can and can't do					
Where to go for more information about your [the patient's name] condition					

**ALL PARTICIPANTS**

6. BEFORE leaving the ICU, did someone close to you (family, friend, caregiver) [you or another family member] receive information about your [the patient's name] transition out of the ICU and how to help care for you [the patient's name]?

- Yes     
  No     
  Unsure     
  N/A There was no family member to be involved / I did not want a family member to be involved.

7. In thinking about the planning & preparation of your [the patient's name] ICU transition, please rate how much:

	1	2	3	4	5
	Not at all	Slightly	Moderately	Very	Completely
you were involved/engaged in the process					
your involvement was as much as you wanted it to be involved.					
your family member or someone close to you was involved/engaged in the process [patient only]					
your family member's involvement was as much as you wanted him/her to be. [patient only]					
your involvement/engagement relative to what [the patient's name] wanted it to be [family only]					

8. How would you rate your OVERALL satisfaction with your [the patient's name] transition from the ICU?

- 1                      2                      3                      4                      5  
 Poor                      Fair                      Good                      Very Good                      Excellent

9. Was the information that you received prior to leaving the ICU enough to help prepare you for your ICU [the patient's name] transition and next steps?

- Yes     
  No     
  Unsure

10. If you received information in writing about your [the patient's name] ICU stay and next steps, do you still have a copy of this written summary? [ask only if Question 3 is 'Yes']

- Yes     
  No     
  Unsure     
  Not applicable

11. Have you looked at this summary for information since leaving the ICU? [ask if Q3 is 'Yes']

- Yes     
  No     
  Unsure     
  Not applicable

ICU to HOME TRANSITIONS ONLY

12. **AFTER** your [the patient's name] discharge from the ICU, how well were you able to [rep the patient's name] follow the discharge information and instructions for the following areas:

	1 Not at all	2 Slightly	3 Moderately	4 Very	5 Completely
Medications and possible supplements (when to take them and why)					
Follow-up appointments/tests – what, when where					
Have you [the patient's name] attended any follow-up appointments since your [the patient's name] discharge from the ICU?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure    If yes, with whom				
Changes to your [the patient's name] diet					
Changes to daily routine (walking, driving, working) – what you [the patient's name] can and can't do					
Where to go for more information about your [the patient's name] condition or questions you had					

## ALL PARTICIPANTS

### DEMOGRAPHICS

12. How old are you? \_\_\_\_\_  Prefer not to answer

13. What is your self-identified gender?

Female     Male     Other     Prefer not to answer

14. What is your highest level of education?

Some high school     High school     Some post-secondary  
 Undergraduate     Graduate

### OPEN-ENDED QUESTIONS

15. Do you have other comments about your experiences transitioning from the ICU?

16. Do you have any suggestions for improving transitions from the ICU?

**CAREGIVER EXPERIENCE of ICU to Ward TRANSITION**

Please answer all questions about your recent experience transitioning from the Intensive Care Unit (ICU). Your response to these questions provides important information to help improve the ICU transition process for patients and families. Your participation is strictly voluntary. You are ~~to~~ free to choose to refuse to answer any question or to discontinue participation at any time. It will not impact your current or future care. **Please check one answer per question.**

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**1. How long has it been since [the patient] transitioned from the ICU?**

- Within a week
- More than a week but less than a month
- More than a month but less than 3 months
- More than 3 months

**2. BEFORE leaving the ICU, did you have a conversation with a member of the ICU team to discuss [the patient's] ICU stay and what your next steps might be?**

- Yes
- No
- Unsure

**3. BEFORE leaving the ICU, did you get information in writing summarizing [the patient's] ICU stay and what the next steps might be?**

- Yes
- No
- Unsure

**4. BEFORE leaving the ICU, how would you rate your understanding about:**

	1	2	3	4	5
	Poor	Fair	Good	Very Good	Excellent
[The patient's] medical condition that brought him/her to the ICU					
Events that happened while [The patient] was in the ICU					
How [the patient's] ICU stay might affect his/her physical and psychological health (short and long-term impact)					

5. BEFORE leaving the ICU, how would you rate your understanding about:

	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
What to expect about [the patient's] care on the hospital ward (e.g., nurse-to-patient ratio, number of patients per room, differences from ICU)					

6. BEFORE leaving the ICU, were you aware of the following information about the unit [the patient] was transitioning to:

- Ward name/medical service  Yes  No  Unsure
- Ward unit number  Yes  No  Unsure
- Ward contact number  Yes  No  Unsure
- Name of ward doctor  Yes  No  Unsure

7. BEFORE leaving the ICU, did you receive the information you needed about [the patient's] transition

- Yes  No  Unsure

8. In thinking about the planning and preparation of [the patient's] ICU transition, how much:

	1 Not at all	2 Slightly	3 Moderately	4 Very	5 Completely
were you involved/engaged in the process (discussions about care, support, and treatment)					
was your involvement/engagement relative to what you wanted it to be					
was your involvement/engagement relative to what [the patient] wanted you to be					

7. How would you rate your OVERALL satisfaction with [the patient's] transition from the ICU?

- 1                      2                      3                      4                      5  
 Poor                      Fair                      Good                      Very Good                      Excellent

9. If you received information in writing about [the patient's] ICU stay and next steps, do you still have a copy of this written summary?

- Yes  No  Unsure

10. Have you looked at this summary for information since leaving the ICU?

- Yes  No  Unsure

## DEMOGRAPHICS

8. How old are you? \_\_\_\_\_  Prefer not to answer
9. What is your gender?  
 Female       Male       Other \_\_\_\_\_
10. What is your highest level of education?  
 Some high school       Highschool       Some post-secondary       Undergraduate       Graduate
11. Do you have other comments about your experience with the ICU transition process?
12. Do you have any suggestions for improving the ICU transition process?

**CAREGIVER EXPERIENCE of ICU to Home TRANSITION**

Please answer all questions about your recent experience transitioning from the Intensive Care Unit (ICU). Your response to these questions provides important information to help improve the ICU transition process for patients and families. Your participation is strictly voluntary. You are free to choose to refuse to answer any question or to discontinue participation at any time. It will not impact your current or future care. **Please check one answer per question.**

1. **How long has it been since [the patient] transitioned from the ICU?**

- Within a week
- More than a week but less than a month
- More than a month but less than 3 months
- More than 3 months

2. **BEFORE leaving the ICU, did you have a conversation with a member of the ICU team to discuss [the patient's] ICU stay and what your next steps might be?**

- Yes
- No
- Unsure

3. **BEFORE leaving the ICU, did you get information in writing summarizing [the patient's] ICU stay and what the next steps might be?**

- Yes
- No
- Unsure

4. **BEFORE leaving the ICU, how would you rate your understanding about:**

	1	2	3	4	5
	Poor	Fair	Good	Very Good	Excellent
[The patient's] medical condition that brought him/her to the ICU					
Events that happened to [the patient] while he/she was in the ICU					
How [the patient's] ICU stay might affect his/her physical and psychological health (short and long-term impact)					

5. BEFORE leaving the ICU, how would you rate your understanding about:

	1 Poor	2 Fair	3 Good	4 Very Good	5 Excellent
[The patient's] prescribed medications - when to take them and why					
The [patient's] follow-up appointments and tests					
Who to contact if you had questions or concerns about the [patient's] condition or treatment					
The [patient's] recommended mobility and activity (and restrictions)					
What to do if you were worried about the [patient's] condition or treatment after discharge from the hospital					
Where to go for more information					

6. BEFORE leaving the ICU, did you receive the information needed to help care for [the patient]?

- Yes       No       Unsure

7. In thinking about the planning and preparation of [the patient's] ICU transition, how much:

	1 Not at all	2 Slightly	3 Moderately	4 Very	5 Completely
Were you involved/engaged in the process (discussions about care, support, and treatment)					
Was your involvement/engagement relative to what <b>you wanted it to be.</b>					
Was your involvement/engagement relative to what <b>[the patient]</b> wanted you to be					

8. How would you rate your OVERALL satisfaction with [the patient's] transition from the ICU?

- 1                      2                      3                      4                      5  
 Poor                      Fair                      Good                      Very Good                      Excellent

9. If you received information in writing about [the patient's] ICU stay and next steps, do you still have a copy of this written summary?

Yes       No       Unsure

10. Have you looked at this summary for information since leaving the ICU?

Yes       No       Unsure

11. **AFTER** [the patient's] discharge from the ICU, how well were you able to help [the patient] follow the discharge information and instructions for the following areas:

	1 Not at all	2 Slightly	3 Moderately	4 Very	5 Completely
Medications and possible supplements (when to take them and why)					
Follow-up appointments/tests – what, when where					
Have you attended any follow-up appointments since your discharge from the ICU?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure      If yes, with whom				
Changes to your diet					
Changes to daily routine (walking, driving, working) – what you can and can't do					
Where to go for more information about your condition or questions you had					

**DEMOGRAPHICS**

9. How old are you? \_\_\_\_\_  Prefer not to answer

10. What is your gender?

Female       Male       Other \_\_\_\_\_

11. What is your highest level of education?

Some high school       High school       Some post-secondary       Undergraduate       Graduate

12. Do you have other comments about your experience with the ICU transition process?

**13. Do you have any suggestions for improving the ICU transition process?**