

Improving racial disparities in unmet palliative care needs among ICU family members with a needs-targeted app intervention: the ICUconnect randomized trial.
NIH U54 MD012530

What is ICUconnect?

The ICUconnect study is a clinical trial. It tests a simple intervention (the ICUconnect app) which is designed to help ICU clinicians deliver 'primary palliative care' to patients & families.

The patients we are targeting are those who receive mechanical ventilation in a Duke ICU for any reason for at least 2 days.

This study does not involve prognostication, goals of care talks, decision making, palliative care consults, etc.

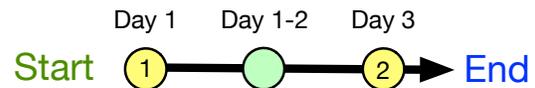
What do I have to do for the study?

It's simple! All you do is:

Day 1: View the family's needs on the app

Day 1-2: Have family meeting to discuss the needs family reported in the app

Day 3: View the new family needs scores to see how well you addressed the needs



- View Needs Score **online** (1-2 min.)
- Family meeting to discuss needs as you wish

How will I know when I need to look at the ICUconnect app?

Don't worry! The app will prompt you via texts/emails to look at new family data as they enter it at T1 (baseline, or 'Time 1') and T2 (2-3 days later, or 'Time 2'). We will also send a reminder after T1 for you to do a family meeting to discuss the needs with the family member.

How much time will this take—and how many families will I work with?

It literally takes 1 minute to view the needs; the only extra time is the family meeting (which would probably happen anyway).

Each ICU attending will have only 5-10 different patient/family member groups over the course of 2-3 years. It is unlikely there will be more than 1 active family member at any time.

Who is doing this?

Christopher Cox (MICU) is leading this study, but representatives from all Duke and DRH ICUs will be part of the study team including Mashaël Al-Hegalan (DRH), Yasmin O'Keefe (Neuro ICU), Krista Haines (SICU), and Robert Harrison (CICU). Please contact Chris at Christopher.cox@duke.edu or at 919-358-6451 any time with any questions.

[A detailed guide](#) on how to actually use the app is on the **next page**.

How to use the ICUconnect app

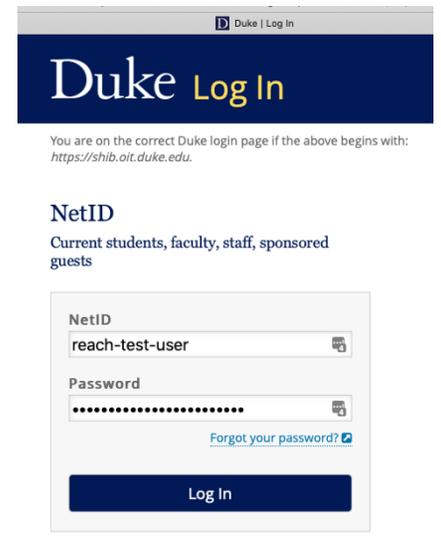
You can either follow the detailed **steps below** or

You can [click on this link](https://vimeo.com/322281042) to watch a 90-second video on how to use the ICUconnect app. The URL for the link is: <https://vimeo.com/322281042>



Step 1: Log in to the ICUconnect web app by either:
Follow the text / email link you are sent **or**
Go to [ICUconnect.duke.edu](https://icucconnect.duke.edu)

Note: you log in to ICUconnect through Duke's Shibboleth system with your personal NetID (e.g., smith00047) and password



Step 2: View family needs scores on your study dashboard
Your dashboard populates with family needs scores as time goes on.

To see new needs scores, click the patient name in the section '**Participants Requiring Attention**' [*highlighted in red in Figure*]

To review previously viewed needs scores, click on the patient name in the section '**Participants**' [*highlighted in orange in Figure*]



To sort needs by severity, click on **T1** (baseline, or 'Time 1') or **T2** (after family meeting, or 'Time 2').
Remember: Needs can range 10 (severe need) to 0 (no need).

To sort needs by change over time, click on **CH** ('change') to magnitude of change in needs.
Remember: A positive change (i.e., needs increased) is bad...and a negative change (i.e., needs decreased) is good.

Click 'T1' to sort
BASELINE needs scores
by severity

Click 'T2' to sort
FOLLOW UP (day 2 or 3)
needs scores by severity

Click 'CH' to sort the
magnitude of change in
needs scores

10 is the highest level of need

0 is the lowest level

Family Needs	T1 11/07/18 12:00am	T2 11/07/18 12:00am	CH
Decision making help	10	6	-4
Respect my culture	9	4	-5
Family stress	8	8	0
Spiritual concerns	8	5	-3
Information needed	8	2	-6
Social support	7	8	+1
Listen & answer my Qs	6	8	+2
Long-term outcome?	5	6	+1
Family custom need:	5	3	-2
Discharge plans	3	2	-1
Patient symptoms	3	6	+3
Financial stress	3	6	+3
Communication issues	0	5	+5
Treatment vs values alignment	0	4	+4
Trust issues	0	6	+6
Long-term outcome?	5	6	+1
Family stress	8	8	0
Patient symptoms	3	2	-1
Family custom need:	5	3	-2
Discharge plans	3	6	+3
Spiritual concerns	8	5	-3
Decision making help	10	6	-4
Respect my culture	9	4	-5
Information needed	8	2	-6
Patient symptoms	3	2	-1

+4 means that the needs score increased by 4 units—this is bad!

-4 means that the needs score decreased by 4 units—this is good!

10 is the highest level of need

0 is the lowest level

Family Needs	T1 11/07/18 12:00am	T2 11/07/18 12:00am	CH
Family stress	8	8	0
Social support	7	8	+1
Listen & answer my Qs	6	8	+2
Decision making help	10	6	-4
Long-term outcome?	5	6	+1
Financial stress	3	6	+3
Trust issues	0	6	+6
Spiritual concerns	8	5	-3
Communication issues	0	5	+5
Respect my culture	9	4	-5
Treatment vs values alignment	0	4	+4
Family custom need:	5	3	-2
Discharge plans	5	3	-2
Information needed	8	2	-6
Patient symptoms	3	2	-1

0 is the lowest level

10 is the highest level of need

0 is the lowest level

Family Needs	T1 11/07/18 12:00am	T2 11/07/18 12:00am	CH
Trust issues	0	6	+6
Communication issues	0	5	+5
Treatment vs values alignment	0	4	+4
Financial stress	3	6	+3
Listen & answer my Qs	6	8	+2
Social support	7	8	+1
Long-term outcome?	5	6	+1
Family stress	8	8	0
Patient symptoms	3	2	-1
Family custom need:	5	3	-2
Discharge plans	3	6	+3
Spiritual concerns	8	5	-3
Decision making help	10	6	-4
Respect my culture	9	4	-5
Information needed	8	2	-6

0 is the lowest level

To see tips about how best to address a specific need with the family member during a family meeting, just click on the **need header**.

To return to your patient list when you are done viewing needs, click the **dashboard** button.

ICUconnect reach-test-user@duke.edu Dashboard Logout

Nathan Riggs representing Megan Hunt

Post Care Survey

How to sort? Click on T1 (Family interview 1), T2 (Family interview 2), or CH (change T1 - T2)
What do need scores mean? 10=highest level of need and 1=lowest level of need

Family Needs	T1	T2	CH
	11/07/18 12:00am	11/07/18 12:00am	
Decision making help	10	6	-4
Respect my culture	9	4	-5
Family stress	8	8	0
Spiritual concerns	8	5	-3
Information needed	8	2	-6
Social support	7	8	+1
Listen & answer my Qs	6	8	+2

Click dashboard to return to your patient list

Click need header to get tips on how to address the need

Fact: Shared decision making is often imperfect in the ICU.
Tip: Use ADAPT: **A**sk if they've heard what to expect; **D**iscover what info about the future would help most; **A**nticipate indecision: 'Most people want to know about prognosis but also don't want to know at the same time -- what about you?'; **P**rovide info (% best/worst/usual case, specific event); **T**rack and respond to emotion. Also, **m**ap patient values on a simple goals of care figure.

Fact: Many families have emotional distress, including in-hospital symptoms of depression, anxiety, and PTSD. Acknowledging emotions can improve communication and relationships.
Tip: Try: **N.U.R.S.E** = **N**ame and validate the emotion ('It seems like you may be upset or maybe even a little angry?'), **U**nderstand ('I can understand your concern'), **R**espect their experience ('I can't imagine how difficult this must be for you'), **S**upport ('I am here to help you in any way'), and **E**xplore ('Could you tell me more?')

Step 3: Complete a brief (3 items) post-T2 survey

After the family completes their follow up (T2) survey, you'll be directed to complete a brief 3-item survey when you log in

Then you can see the T2 needs

Step 4: You're done!