

FS-ICU 24R Electronic Database Instruction Manual for Healthcare Professionals

A guide to evaluating your ICU

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Step 1: REDCap™ and Site Registration

What is REDCap™?

REDCap™ is a web-based electronic data capture system that will be used to collect and manage your FS-ICU questionnaire data. The program is widely used in healthcare settings, and allows for:

- **Restricted database access**, so that only designated staff can access, view and modify the data.
- **Online surveys** that allow participants to fill out questionnaires online and automatically store the collected data in the REDCap™ database.
- **Manual data entry** by staff with access to the database.

Registering your site with REDCap™

- You will begin by registering your individual ICU, which will provide you with access to our REDCap™ database.
- To register, please complete the form located at <https://ceru.hpcvl.queensu.ca/randomize/FSICU/registration.php>
 - Detailed instructions for completing this form can be downloaded using the link provided at the top of the form.
 - *Please note that the system cannot handle special characters (i.e. é, ç, ö, and ã), so please avoid their use*
- Once your site registration is complete, each individual you entered as Primary REDCap™ Users will receive an email with their username, temporary password, and link to REDCap™.
- If you encounter difficulties with registration or wish to add additional users after you have already registered, please email shawna.froese@queensu.ca

Logging in to REDCap™

Once your ICU is registered, REDCap™ can be directly accessed at:

https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/



Log In

Please log in with your user name and password. If you are having trouble logging in, please contact [CERU Support](#).

Username:	<input type="text"/>
Password:	<input type="password"/>
<input type="button" value="Log In"/>	Forgot your password?

Step 2: Participant Recruitment

Note: In order to obtain bench-marked reports, the method of data collection has to mirror what has been done with other data collection coming from other sites. To standardize this, we recommend that the FS-ICU questionnaire should be administered upon ICU discharge for Family Members of survivors (or within 48 hours), and 3-6 weeks after death for Family Members of non-survivors. In order to have a sample large enough to be representative of your site's performance, to obtain a benchmarked report, 50 questionnaires must be collected.

1. Assess your ICU patients to determine which patients have available family members and will leave the ICU within the next couple of days (due to discharge or death).
2. Approach the family member and introduce the questionnaire.
3. Inform them that their results will be kept confidential and will not be communicated back to the doctors and nurses looking after the patient.

Please see pages 13-14 of this document for email/mail templates if you are sending the participant the questionnaire. In the case of an ICU non-survivor, we ask that you kindly express compassion, sympathy and patience to the family-member.

Patient Characteristics

Many ICUs are interested in relating family satisfaction levels to particular patient characteristics. For example, some ICUs want to see if patient death corresponds to higher/lower levels of family satisfaction, or if some ethnic groups report higher/lower levels of family satisfaction. Our REDCap™ system allows you to collect patient data that will be associated with your family satisfaction data if you are interested in doing so. If you are, you will need to track which patients correspond to which participant study ID (remember the participant is the *family member* of the patient). Please refer to page 9 to see how this information can eventually be entered in REDCap™, and refer to [our website](#) to see a paper copy of this form and the information that it can help you collect.

Keeping Track of Participants

It is important that you keep track of patients, their participating family member, the family member's email address, and the corresponding Study ID. Please refer to [our website](#) for an example of a log that can help track Family Members, email addresses, Study IDs, etc.

Step 3: Administering the Questionnaire and Collecting Data

The questionnaire should be administered upon ICU discharge for Family Members of survivors (or within 48 hours), and 3-6 weeks after death for Family Members of non-survivors.

There are three different methods of administering the questionnaire and collecting data:

- A. **Online Survey with a Participant-specific link** – each participant has their own unique link to the survey
- B. **Online Survey with a Site-specific link** – your site uses the same link to the survey for all participants at their site
- C. **Paper Questionnaire and Manual Data Entry**

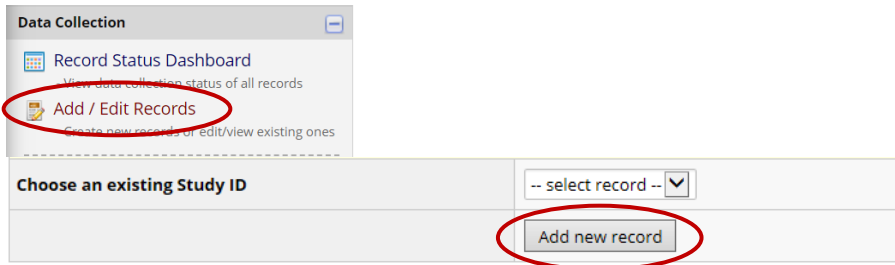
You can use one or all of these methods at your site. Which method(s) you use depends on your end goals, the preferences/needs of the participant, and your site.

The Three Different Methods – an Overview:

A: Online Survey – Participant-specific link	B: Online Survey – Site-specific link	C: Paper Questionnaire and Manual Data Entry
Your site generates participant-specific link that can be opened on a computer or tablet on site or emailed to the participant to complete at home. Responses are saved to the REDCap™ database.	Your site saves their site specific link to the survey on computers or tablets located on site and participants are asked to complete the questionnaire. Responses are saved to the REDCap™ database.	Print a questionnaire to hand or mail to participants. Once returned, staff manually enter the questionnaire data into the REDCap™ database.
Advantages: <ul style="list-style-type: none"> • Each participant has a known Study ID • FS-ICU data can be associated with Patient Characteristics • Family members of non-survivors can be emailed their survey link 3-6 weeks after death and responses can be tracked 	Advantages: <ul style="list-style-type: none"> • Once setup, this method is quick, requiring minimal preparation by the site 	Advantages: <ul style="list-style-type: none"> • Multiple languages can be used • Each participant has a known Study ID • FS-ICU data can be associated with Patient Characteristics • Family members of non-survivors can be mailed the questionnaire 3-6 weeks after death and responses can be tracked
Disadvantages: <ul style="list-style-type: none"> • Creation of participant-associated links requires preparation by site • You will need to maintain participant log 	Disadvantages: <ul style="list-style-type: none"> • You cannot track responses • You will NOT be able to link the participant to a Study ID • NO Patient Characteristics • Emailing the link to participants is NOT recommended 	Disadvantages: <ul style="list-style-type: none"> • Staff required to manually enter questionnaire data into the REDCap™ database • You will need to maintain participant log

METHOD A: Online Survey with a Participant-specific link

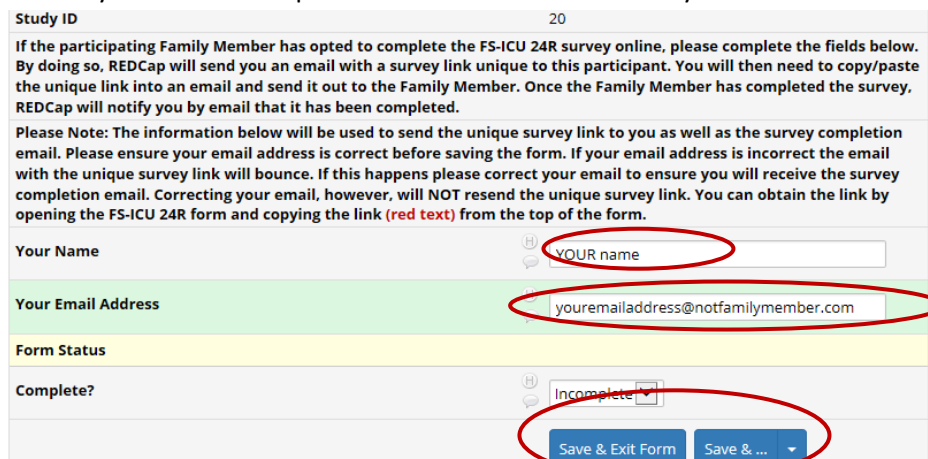
1. On a computer, log into REDCap™
2. Select “FS-ICU 24R” under “My Projects”
3. Add a new record by navigating to the left sidebar, clicking Add/Edit Records, then Add new record



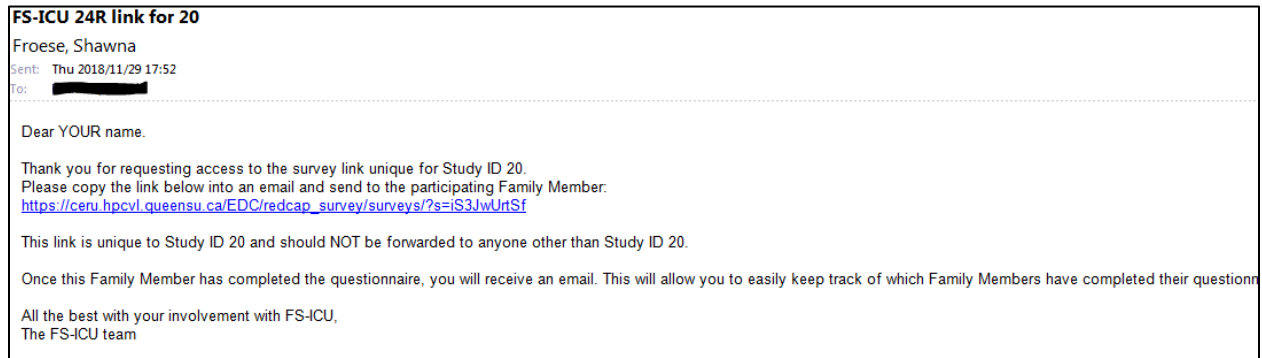
4. Click the circle for the “Send FS-ICU link” form

Data Collection Instrument	Status
FS-ICU 24R (survey)	<input type="radio"/>
Send FS-ICU 24R Link	<input checked="" type="radio"/>
Patient Characteristics	<input type="radio"/>

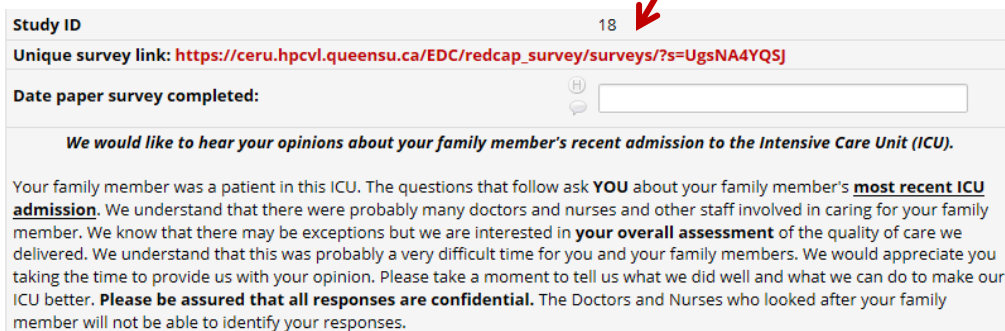
5. Enter **YOUR** name and **YOUR** email address (**NOT** the Family Member’s). This ensures that the data in REDCap™ is anonymous and should comply with any privacy legislation you are required to follow.
 - The link is **initially** sent to *you* so that you can send a personalized email to the Family Member, rather than sending each family member a generic message (we want to maintain sensitivity to participants, especially those whose loved one has died)
 - By sending the email yourself, you will know if a family member’s email has bounced and can take action if it does.
 - Also, if the email is from somebody that the family members recognizes, they are less likely to assume it is spam and are more likely to complete the survey.
 - Lastly, filling in this form with your email address will allow for a confirmation message to be sent to you once the questionnaire is complete.
6. Click any of the “Save” options to have the email sent to you.



7. Check your inbox for the email containing the family member’s unique survey link



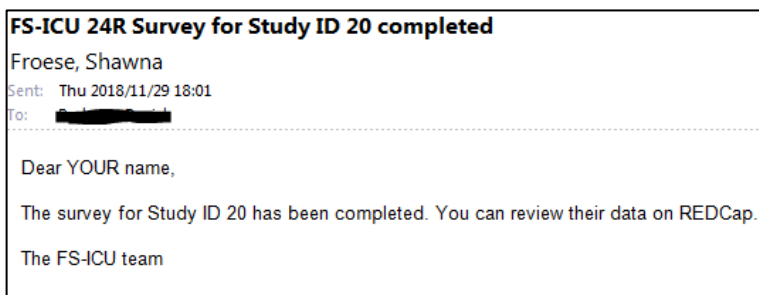
8. Copy the link, paste it into a personalized email, and send it to the family member’s email address
- Sample emails can be found on [our website](#) or on pages 13-14 of this document and can be customized to align with your site’s requirements. Please express compassion and sympathy, especially to those whose Family Member had died during the ICU stay.
9. If for some reason you did not get the email, but completed the “Send FS-ICU link” form, you can also find the link at the top of the record’s “FS-ICU 24R” REDCap™ form. The link will be in red, and can be copied and sent to the participant.






10. Remember to record the Study ID in your participant log.

Tracking Digital Survey Completion:







- When the family member accesses the link and completes the survey, you will receive a confirmation email that will look like this:



- This message will be sent to the email you inputted in step 5 on page 5 (which should be your own email or your ICU’s designated FS-ICU email)
- You can also track completed surveys in REDCap™, as shown below:

Data Collection Instrument	Status
Send FS-ICU 24R Link	
FS-ICU 24R (survey)	
Patient Characteristics	

Legend for status icons:

-  Incomplete  Incomplete (no data saved) ?
-  Unverified  Partial Survey Response
-  Complete  Completed Survey Response

- If participants have not yet responded to the survey, send them a reminder. We suggest every 2 weeks, up to 3 times.

METHOD B: Online Questionnaire with a Site-specific link

This is the simplest way to administer the questionnaire, but should be limited to on site completion by participants.

1. Within 2-3 business days of registering, you will receive an email with your site-specific link.
 - If you do not receive your link, please email shawna.froese@queensu.ca to request access to your site-specific link.
 - Note that the link should only be shared with **your staff**. Since this link is designed to be used for repeated submissions, it is possible if a participant has the link on their own device that they could complete the questionnaire multiple times. If you need to send a link to the questionnaire to a participant, we suggest you use Method A as the Participant-specific links may only be used once.
2. Once you have your link, you can create a bookmark on your computer or tablet’s browser to easily take participants to the questionnaire.
 - You can also have the link pasted in a “Note” or a Word document
 - You can also save the link as a desktop icon
3. When a participant is ready to complete a questionnaire, click on the link, and pass them control of the computer or tablet
4. When they are finished, thank them for their time and feedback, and take back the computer or tablet

If using an iPad, the following link can help limit you set limitations for your browser to restrict participants from navigating to other websites: <https://www.imore.com/how-block-specific-websites-being-accessed-safari-iphone-and-ipad>. Other devices may be similarly restricted using parental controls, consult your IT department for help if required.

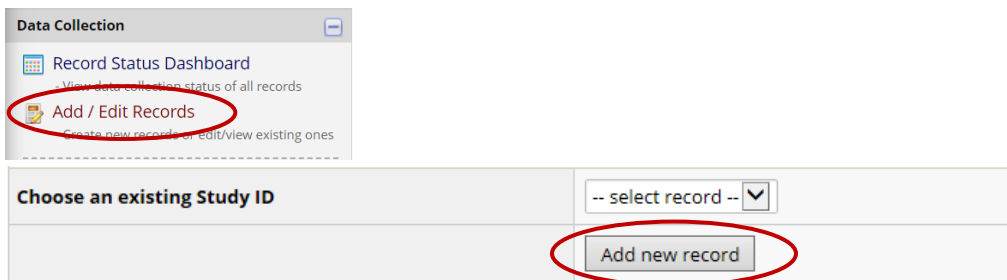
METHOD C: Paper Questionnaire and Manual Data Entry

You can personally hand the questionnaire over to family members of ICU survivors and arrange to pick it up or provide a safe place for them to drop it off.

For family-members of non-survivors, you can mail the questionnaire 3-6 weeks after the patient’s death, with a letter that expresses sympathy and compassion (see a template on page 14 of this document or on [our website](#)). If mailing the questionnaire, please include a stamped, addressed return envelope, and wait 4 weeks to send them a second questionnaire if they have not responded.

Upon receiving a Paper Questionnaire:

1. On a computer, log into REDCap™
2. Select “FS-ICU 24R” under “My Projects”
3. Add a new record by navigating to the left sidebar, clicking Add/Edit Records, then Add new record



4. When you receive the completed paper survey click the “FS-ICU 24R” form:

Data Collection Instrument	Status
FS-ICU 24R (survey)	<input type="radio"/>
Send FS-ICU 24R Link	<input checked="" type="radio"/>
Patient Characteristics	<input type="radio"/>


Note: If the family member chose to complete the survey on paper there is no need to complete the “Send FS-ICU link” form.


5. Enter all of the family member’s responses into the form, and save:


PART 1: SATISFACTION WITH CARE


Please select the response that best reflects your views. If the question does not apply to your family member's stay then select 'Not Applicable' (N/A).


How did we treat your family member (the patient)?
How satisfied are you with...


Very Dissatisfied
1


Slightly Dissatisfied
2


Mostly Satisfied
3


Very Satisfied
4


Completely Satisfied
5

N/A
-

1. Concern and Caring by ICU Staff?
The courtesy, respect and compassion your family member (the patient) was given.

* must provide value

reset

Step 4: Patient Characteristics (*optional*)

As mentioned above, many ICUs are interested in relating family satisfaction levels to particular patient characteristics. If your ICU is interested in doing so, a *staff member* (NOT a participant/patient family member) will need to enter the Patient Characteristic Data into REDCap™.

Please not that Method B does NOT allow you to track which Study ID is associated with which patient/participant pairing. This means that you should limit your site to Methods A and C if you are interested in linking a participant’s family satisfaction data with patient characteristics.

As seen here, a Patient Characteristics Form for each study subject can be found on REDCap™:

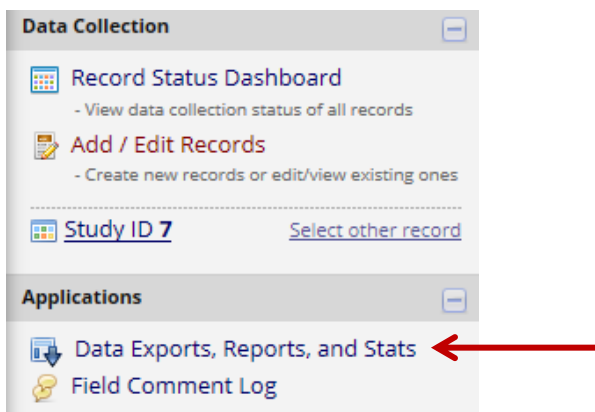
Data Collection Instrument	Status
FS-ICU 24R (survey)	<input type="radio"/>
Send FS-ICU 24R Link	<input type="radio"/>
Patient Characteristics	<input checked="" type="radio"/>

- This information is extracted from the patient chart and can be entered any time prior to requesting a benchmarked report.
- We suggest waiting until the survey has been completed so you do not waste time collecting data on a patient whose family member never completes the survey.
- A PDF of the form can be downloaded and printed from [our website](#).

Step 5: Viewing Your Data

Exporting your Data from REDCap™

- To view your data, click on the “Data Exports, Reports, and Stats” link on the left-side navigation bar in REDCap™.



- The Export Data button will allow you to download a copy of your data in various formats (Excel, SAS, SPSS, etc.)
- You can download data for all forms (FS-ICU and patient characteristics) or for only one of the forms

- For Excel downloads, we suggest downloading raw data rather than a sheet with labels, because the labels include the name of the Emoticon image for each question

My Reports & Exports		
	Report name	View/Export Options
A	All data (all records and fields)	View Report Export Data Stats & Charts
B	Selected instruments (all records)	Make custom selections
1	FS-ICU 24R	View Report Export Data Stats & Charts
2	FS-ICU 24R & Patient Characteristics	View Report Export Data Stats & Charts

- Selecting View Report will allow you to see a table with each participants responses (Emoticons will also be in the table, allowing you to scan through it more quickly)
- Selecting Stats and Charts will allow you to go through each questionnaire item and see how many times each response option was selected. REDCap™ also provides bar graphs and pie charts to visualize this. Although this helps present your data to you, this is all automatically generated by REDCap™, so it does not look perfect.
- When using Method B a record will be created each time the link is opened regardless of whether or not the questionnaire is completed. This will mean you may see many records with no data and will require some cleanup before you can analyse.

Requesting a report of your data from the FS-ICU team

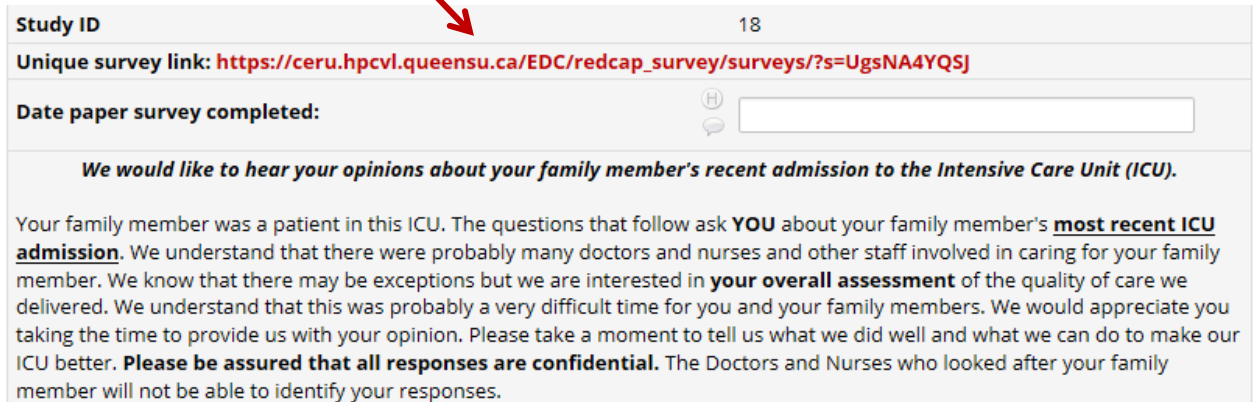
FS-ICU’s REDCap™ system is excellent for collecting and tracking data. As outlined above, you are also able to easily export your data from a variety of methods. Unfortunately, looking at raw data does not quite help you gauge your ICU’s performance. In order for this data to be useful, it would need to be presented in a report or graph.

- If you would like to save the time and effort of converting your data, our statistics team can create a visual report that clearly shows how your site is performing on each FS-ICU item, and overall.
- We can also provide a **benchmarked report**. This means our statistics teams takes data from all sites that have conducted FS-ICU (around 100 worldwide) and shows how your site ranks on each FS-ICU item and overall. To learn more about Benchmarking, please see [our website](#).
- If you collected data on Patient characteristics, our statistics team can create a report that compares one patient subgroup’s family satisfaction vs. that of another patient subgroup. Once common example is comparing family satisfaction for ICU survivors vs. non-survivors.
- Our statistics team can also create other comparison reports, such as comparing your ICU’s past performance to your current performance. This can help show improvements in your services over time.

The FS-ICU REDCap™ system is free to use, as we encourage ICU’s to evaluate their performance by collecting and exporting data. However, there is a fee if you would like our Statistics team to prepare a report for you. Please see [our website](#) for more information.

Troubleshooting

- **(Method A)** I did not get the email from REDCap™/Shawna Froese that contains the unique survey link. This could happen if an error was made entering your email address, or a technical error (i.e. your firewall blocked the email).
 - If you completed the “Send FS-ICU link” form, the link will also be available at the top of the “FS-ICU 24R” REDCap™ form. The link will be in red, and can be copied and sent to the participant.



Study ID 18

Unique survey link: https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ

Date paper survey completed:

We would like to hear your opinions about your family member's recent admission to the Intensive Care Unit (ICU).

Your family member was a patient in this ICU. The questions that follow ask **YOU** about your family member's **most recent ICU admission**. We understand that there were probably many doctors and nurses and other staff involved in caring for your family member. We know that there may be exceptions but we are interested in **your overall assessment** of the quality of care we delivered. We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion. Please take a moment to tell us what we did well and what we can do to make our ICU better. **Please be assured that all responses are confidential.** The Doctors and Nurses who looked after your family member will not be able to identify your responses.

- While in REDCap™, check the “Send FS-ICU link” form to see if you made a mistake entering your email address. If the email address was incorrect, that would explain why you did not receive the email. You should correct the email address to ensure you receive the survey completion email.
- **(Method A)** The Family Member contacted me saying they partially completed the online survey but closed the survey before finishing.
 - Inform them that they can still complete the survey by following the link again; however, they will have to start the survey from the beginning.
- **(Method A)** The family member changed their mind about the digital survey and wants to complete the paper version of the survey. However, they already opened the questionnaire link.
 - Collect the family member’s completed paper questionnaire using the instructions from 3B above.
 - You will not be able to enter their data in the form as they’ve ‘activated’ the survey, instead you will use their participant-specific link to access their survey and enter the data.

- To access their survey, use their unique link. This can be found on the email that REDCap™ sent to you, or on the “FS-ICU 24R” REDCap™ form (at the top in red text)

Study ID	18
Unique survey link:	https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ
Date paper survey completed:	<input type="text"/>

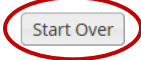
We would like to hear your opinions about your family member's recent admission to the Intensive Care Unit (ICU).

Your family member was a patient in this ICU. The questions that follow ask **YOU** about your family member's **most recent ICU admission**. We understand that there were probably many doctors and nurses and other staff involved in caring for your family member. We know that there may be exceptions but we are interested in **your overall assessment** of the quality of care we delivered. We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion. Please take a moment to tell us what we did well and what we can do to make our ICU better. **Please be assured that all responses are confidential.** The Doctors and Nurses who looked after your family member will not be able to identify your responses.

- Click “Start Over”

You have partially completed this survey.

You have not completed the entire survey, and your responses are thus considered only partially complete. For security reasons, you will not be allowed to continue taking the survey from the place where you stopped. So you have the option to 1) leave your survey responses unchanged as they are, or 2) you may start the survey over from the beginning so that you may complete it (this will delete all your previously existing responses when you begin again). To start the survey again, click the button below.



- Go through the online survey version of the questionnaire, entering the results that the participant has written on their paper form.

Email Templates

NOTE:

Although these templates facilitate the process, we recommend further personalizing them to properly represent your ICU, and to be more compassionate to the Family Members of your ICU patients.

For example, if you know the relationship to the family member, please apply this to the letter (i.e. say “your husband” instead of “your family member”)

If you directly spoke to the family member, you can mention this too. We recommend that the person that sends the email is somebody who has spoken with the family member (and ideally the person who took down their email address).

Template 1 – Family Members of ICU Survivors (to be sent at ICU discharge)

(ICU LOGO IF POSSIBLE)

Dear **(FAMILY MEMBER NAME)**,

Your Family Member was recently a patient at the **(ICU NAME)** at **(HOSPITAL NAME)**. We understand that this can be a difficult experience for you and your family member. At **(ICU NAME)**, we strive to optimize the care given to our patients, and improve the experiences of their family members.

Family members of patients provide valuable input on ICU performance, and we are asking that you take 10 minutes to complete the Family Satisfaction with the Intensive Care Unit questionnaire (FS-ICU), a widely recognized tool in the field of critical care medicine. Completing this questionnaire informs us of our strengths and weaknesses, and gives us a direction on how we can deliver better service to patients and their family members.

Please follow this link to complete the questionnaire: **(link)**

You can only complete the questionnaire once, and will have to start from the beginning if you exit the webpage.

If you have any questions, feel free to email me.

We wish you and your family member all the best,

YOUR NAME

YOUR POSITON

YOUR ICU AND HOSPITAL

Template 2 – Family Members of Non-Survivors (to be sent 3-6 weeks after death)
(ICU LOGO IF POSSIBLE)

Dear **(FAMILY MEMBER NAME)**,

Your Family Member was recently a patient at the **(ICU NAME)** at **(HOSPITAL NAME)** before they passed. We understand that this was a difficult experience for you, and offer our sincere condolences. We wish you and your family our best wishes at this time.

At **(ICU NAME)**, we strive to optimize the care given to our patients, and improve the experiences of their family members.

Family members of patients provide valuable input on ICU performance, and we are asking that you take 10 minutes to complete the Family Satisfaction with the Intensive Care Unit questionnaire (FS-ICU), a widely recognized tool in the field of critical care medicine. Completing this questionnaire informs us of our strengths and weaknesses, and gives us a direction on how we can deliver better service to patients and their family members.

Please follow this link to complete the questionnaire: **(link)**

You can only complete the questionnaire once, and will have to start from the beginning if you exit the webpage.

If you have any questions, feel free to email me.

Best wishes,

YOUR NAME

YOUR POSITON

YOUR ICU AND HOSPITAL