

FS-ICU 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:

- **Manual data entry** by somebody with control over the database
- **Providing links to individual external surveys.** This allows for participants to fill out the questionnaire online and for the data to automatically be loaded in the REDCap™ database.
- **Restricting database access** so that only the specifically registered staff can access, view and modify the database.

Registering your site with REDCap™

- You will begin the data collection process by registering your individual ICU to our worldwide 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, please email shawna.froese@kingstonhsc.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:

Password:

Log In

[Forgot your password?](#)

Step 2: Participant Recruitment

The FS-ICU questionnaire should be administered upon ICU discharge for Family Members of survivors, and 3-6 weeks after death for Family Members of non-survivors. In order 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. **You can either ask for their email address so you can send them the digital survey or give them a paper copy of the survey (with instructions on how to return the survey to you)**
3. Inform them that their results would be kept confidential and would not be communicated back to the doctors and nurses looking after the patient.

Please see page 16 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.

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.

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 correspond 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 (and please remember that participant is the *family member* of the patient). Please refer to page 11 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.

Step 3: Administering the Questionnaire and Collecting Data

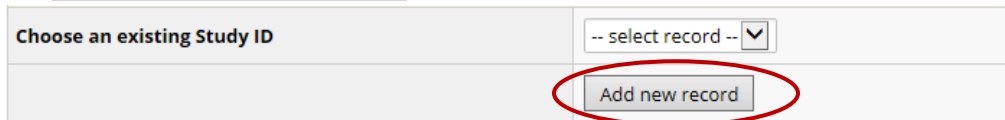
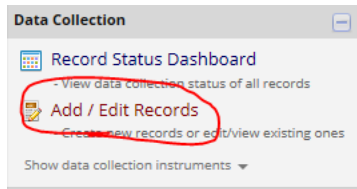
The questionnaire should be administered upon ICU discharge for Family Members of survivors, and 3-6 weeks after death for Family Members of non-survivors.

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

- A. Sending participants the digital questionnaire (via an external REDCap™ link)
- B. Presenting the questionnaire on a Tablet (e.g. iPad)
- C. Administering a paper copy and the manually entering data

OPTION A: Sending the Digital 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, and clicking Add/Edit Records, then Add new record



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

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

5. Enter **YOUR** name and **YOUR** email address (NOT the Family Member’s)

- 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

Study ID	20
<p>If the participating Family Member has opted to complete the FS-ICU 24R survey online, please complete the fields below. By doing so, REDCap will send you an email with a survey link unique to this participant. You will then need to copy/paste the unique link into an email and send it out to the Family Member. Once the Family Member has completed the survey, REDCap will notify you by email that it has been completed.</p> <p>Please Note: The information below will be used to send the unique survey link to you as well as the survey completion email. Please ensure your email address is correct before saving the form. If your email address is incorrect the email with the unique survey link will bounce. If this happens please correct your email to ensure you will receive the survey completion email. Correcting your email, however, will NOT resend the unique survey link. You can obtain the link by opening the FS-ICU 24R form and copying the link (red text) from the top of the form.</p>	
Your Name	<input type="text" value="YOUR name"/>
Your Email Address	<input type="text" value="youremailaddress@notfamilymember.com"/>
Form Status	
Complete?	<input type="text" value="Incomplete"/>
<input type="button" value="Save & Exit Form"/> <input type="button" value="Save & ..."/>	

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

FS-ICU 24R link for 20

Froese, Shawna
 Sent: Thu 2018/11/29 17:52
 To: [REDACTED]

Dear YOUR name.

Thank you for requesting access to the survey link unique for Study ID 20. Please copy the link below into an email and send to the participating Family Member.
https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys?s=IS3JwUrtSf

This link is unique to Study ID 20 and should NOT be forwarded to anyone other than Study ID 20.

Once this Family Member has completed the questionnaire, you will receive an email. This will allow you to easily keep track of which Family Members have completed their questionnaire.

All the best with your involvement with FS-ICU,
 The FS-ICU team

8. Copy the link, paste it into a personalized email, and send it to the family member’s email address

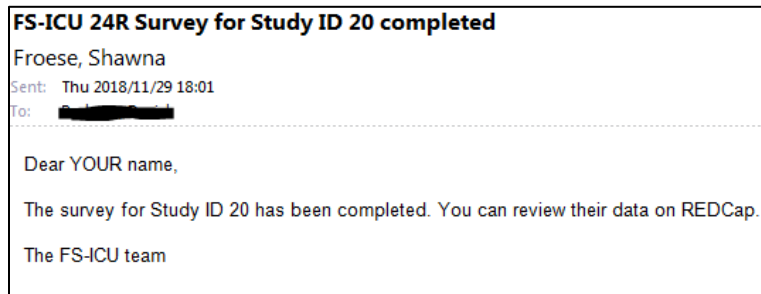
- A sample email template can be found on [our website](#) or on page 16 of this document and can be customized for your site. Please express compassion and sympathy, especially to those whose Family Member had died during the ICU stay.

9. If 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.

Study ID	18
Unique survey link:	https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys?s=UgsNA4YQSJ
Date paper survey completed:	<input type="text"/>
<p><i>We would like to hear your opinions about your family member's recent admission to the Intensive Care Unit (ICU).</i></p> <p>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.</p>	

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 6 on the previous page (which should be your own email or your ICU’s designated FS-ICU email)
- You can 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:

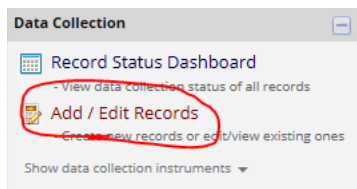
Incomplete	Incomplete (no data saved) ?
Unverified	Partial Survey Response
Complete	Completed Survey Response

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

OPTION B: Providing the Questionnaire on a Tablet (e.g. iPad)

Prepopulating iPads with questionnaire links

1. Please ensure each iPad has a functional email address
 - We recommending making your own gmail for conducting FS-ICU (e.g. muscfsicu@gmail.com). This way you will easily be able to retrieve survey emails, and not mix in other kinds of emails.
2. On a computer, log into REDCap™
3. Select “FS-ICU 24R” under “My Projects”
4. Add a new record by navigating to the left sidebar, and clicking Add/Edit Records, then Add new record



Choose an existing Study ID -- select record --

Add new record

5. Click the grey ‘dot’ for the “Send FS-ICU link” form

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

6. Complete the form, ensuring that the email is the one that is associated with the iPad(s). We will continue using for muscfsicu@gmail.com for our example.

Please Note: The information below will be used to send the unique survey link to you as well as the survey completion email. Please ensure your email address is correct before saving the form. If your email address is incorrect the email with the unique survey link will bounce. If this happens please correct your email to ensure you will receive the survey completion email. Correcting your email, however, will NOT resend the unique survey link. You can obtain the link by opening the FS-ICU 24R form and copying the link (red text) from the top of the form.

Your Name

Your Email Address

Form Status

Complete?

- The “Your Name” field does not matter here, since only the ICU staff administering the questionnaire will see the email. Therefore you can simply put: “ICU Staff” as the name (make sure it is filled though)


7. Continue repeating the steps: adding as many records as you need and filling out the “Send FS-ICU 24R Link” form with the proper email address
 - The iPads email inbox (muscfsicu@gmail.com in our example) will then have several emails containing links for individual participant records

Administrating the questionnaire on an iPad

8. When ready to administer the questionnaire, access the iPad’s designated inbox for the FS-ICU (e.g. Gmail and muscfsicu@gmail.com) and click an unopened email titled “FS-ICU 24R link for x”

FS-ICU 24R link for 26 Inbox x

Shawna.Froese@kingstonhsc.ca

 to me ▾

Dear ICU Staff.


Thank you for requesting access to the survey link unique for Study ID 26.
Please copy the link below into an email and send to the participating Family Member:
https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=gAWBAAhbVS

This link is unique to Study ID 26 and should NOT be forwarded to anyone other than Study ID 26.

Once this Family Member has completed the questionnaire, you will receive an email. This will allow you to

All the best with your involvement with FS-ICU,
The FS-ICU team

9. Click the link, and the unique questionnaire connected to that particular study ID (number 26 in this case) will be ready to be navigated by the participant. The opening page of the questionnaire will look like this:




FS-ICU 24R

**FAMILY SATISFACTION
WITH CARE IN THE ICU®**

How are we doing?

Resize font:



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.

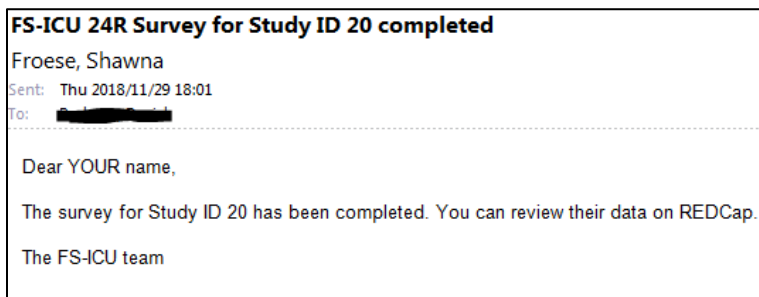
Next Page >>

Housekeeping for iPad use

- Nurses should use a log to take down which Study ID number is given to the Family Member of which patient. The Study ID number will be provided in the email with the FS-ICU link. Logs are encouraged for using FS-ICU regardless of whether or not iPads are used.
- It would be wise to ensure that the emails for unused questionnaire links remain “Unread”/“Unopened” so that Nurses know which emails to pick for questionnaire links
 - If somebody accidentally opens an Link email, but does not actually use the link, they should mark the email as “Unread”/“Unopened”
- REDCap will send a confirmation receipt for completed questionnaires. These can be deleted by the administrative staff to clean up the inbox.
- If a questionnaire has been completed, then the email with its link can be deleted, since the link is void anyway. This will help clean up the inbox as well.

Tracking Digital Survey Completion:

- When the family member accesses the link and completes the survey, your designated FS-ICU email should receive the following message:



- This message will be sent to the email you inputted in step 6 of the iPad instructions
- You can 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

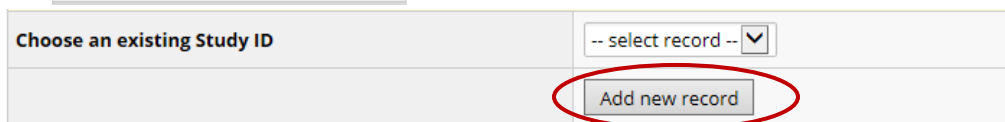
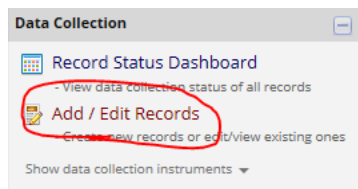
OPTION C: Entering Paper Surveys

You can personally hand the questionnaire over to family members of ICU survivors and arrange to pick it up if preferred.

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 16 of this document, or on [our website](#)). If mailing the questionnaire, please use a stamped, address returned envelope, and wait 4 weeks to send them a second questionnaire if they have not responded.

Upon receiving a Paper Questionnaire:

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



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

NEW Study ID 21

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


6. 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...


Poor
1


Fair
2


Good
3


Very Good
4


Excellent
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

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™.

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

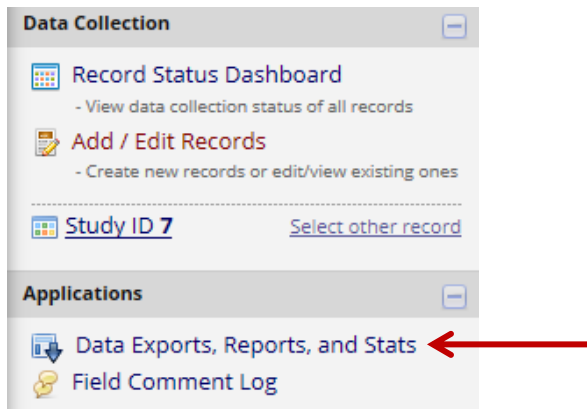
Data Collection Instrument	Status
Send FS-ICU 24R Link	<input type="radio"/>
FS-ICU 24R <i>(survey)</i>	<input type="radio"/>
Patient Characteristics	<input checked="" type="radio"/>

- This information 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 at [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

- 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.

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

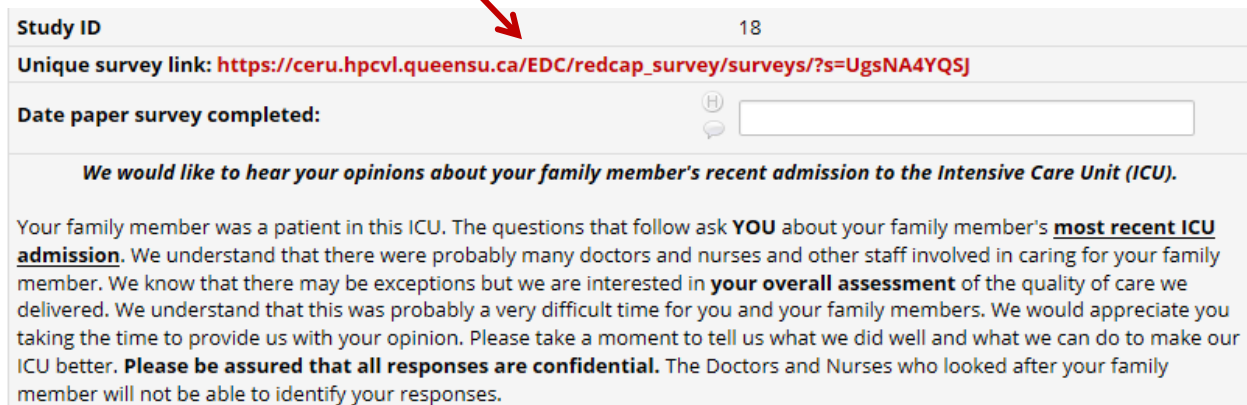
FS-ICU's REDCap™ system is excellent for collecting and tracking data. As outlined above, you are also able to easily export your data from a variety of methods. Unfortunately, looking at raw data does not quite help you gauge your ICU's performance. In order for this data to be useful, it would need 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. One 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 performance of a past time period to a current time period. This can help show improvements of your service 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, the extra work in having our Statistics team readily develop these teams will be charged. Please see [our website](#) for more information.

Troubleshooting

- I did not get the email from REDCap/Shawna Froese that contains the unique survey link (this could arise from an error inputting your email address, or a tech error)
 - 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:	<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.

- 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.
- 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.
- 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 access the 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"/>

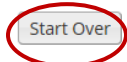
We would like to hear your opinions about your family member's recent admission to the Intensive Care Unit (ICU).

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 web version of the questionnaire, entering the results that the participant had 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