



## **FS-ICU Electronic Database Instructions for ICU Professionals**

### **1. Site Registration**

- Registering your site will give you access to REDCap (the electronic data capture system).
- 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.

### **2. Recruitment**

- **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.**
- Assess your ICU patients to determine who may be discharged or may die in the next couple of days and has an available family member.
- 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)**
- 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 the end 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.**
- 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.
- In order to obtain a benchmarked report, 50 surveys must be collected

### 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.

#### OPTION A: Sending the Digital Survey

- Log into REDCap
- Select "FS-ICU 24R" under "My Projects"
- Add a new record

Choose an existing Study ID	-- select record --
	<b>Add new record</b>

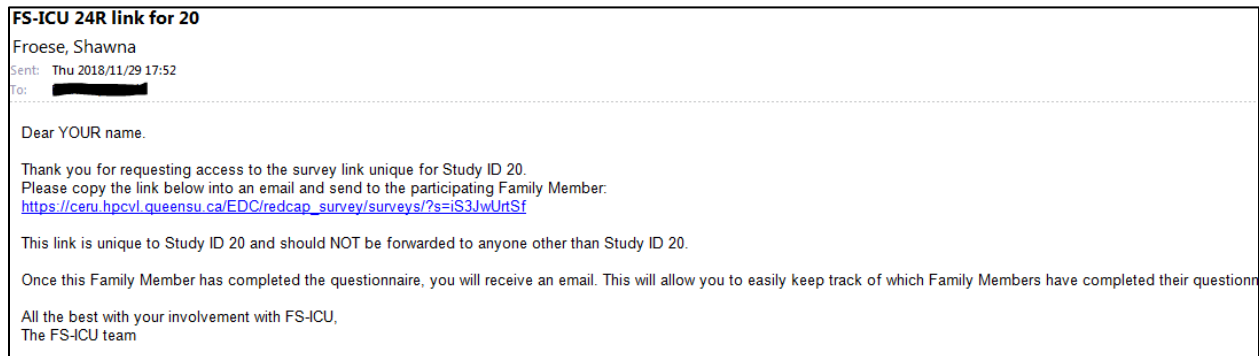
- Click the grey 'dot' for the "Send FS-ICU link" form

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

- Enter **YOUR** name and **YOUR** email address (**NOT** the Family Member's)
- 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"/>
<b>Form Status</b>	
Complete?	<input type="text" value="Incomplete"/>
<input type="button" value="Save &amp; Exit Form"/> <input type="button" value="Save &amp; ..."/>	

- Check your inbox for the email containing the family member’s unique survey link
  - The link is sent to *you* so that you can send a personalized email to the Family Member, rather than having REDCap send the same generalized email to all Family Members of all sites that use our database
  - 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.
  - Sample email that you would receive:



- Copy the link, paste it into an email, and send it to the family member’s email address
  - A sample email template can be found on our website or on the bottom 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.
- 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 “FS-ICU 24R” REDCap form. The link will be in red, and can be copied and sent to the participant.

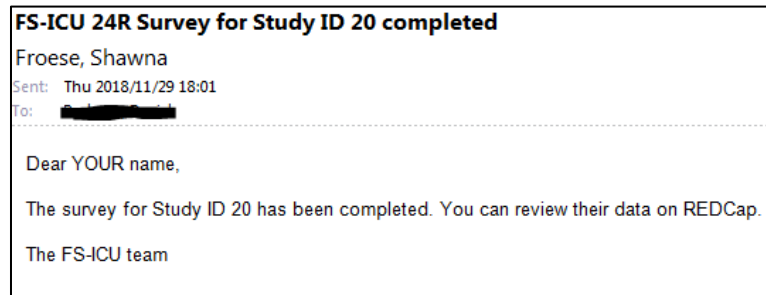
<b>Study ID</b>	18
<b>Unique survey link:</b>	<a href="https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ">https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ</a>
<b>Date paper survey completed:</b>	<input type="text"/>

***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.

- **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:



- 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
-  Unverified
-  Complete
-  Incomplete (no data saved) ?
-  Partial Survey Response
-  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: Entering Paper Surveys

- You can personally hand the questionnaire over to family members of ICU survivors and arrange to pick it up.
- 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 at the bottom 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.
- Log into REDCap
- Select “FS-ICU 24R” under “My Projects”
- Add a new record

Choose an existing Study ID	-- select record --
	<b>Add new record</b>

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


- Enter 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

#### 4. Patient Characteristics

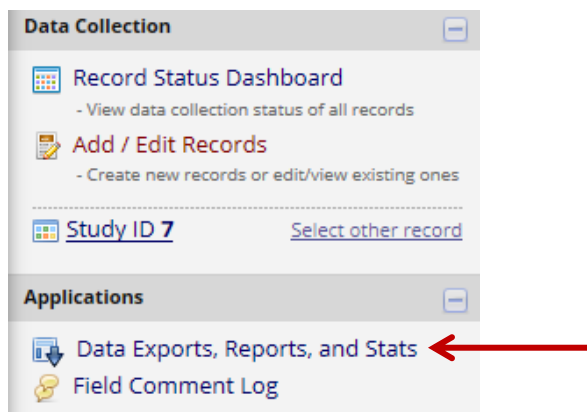
- If you are interested in tracking Patient Characteristics, you can enter them in REDCap via the Patient Characteristics form:

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

- This can be done 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

#### 5. Viewing Your Data

- 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	<b>All data</b> (all records and fields)	<input type="button" value="View Report"/> <input type="button" value="Export Data"/> <input type="button" value="Stats &amp; Charts"/>
B	<b>Selected instruments</b> (all records)	<input type="button" value="Make custom selections"/>
1	FS-ICU 24R	<input type="button" value="View Report"/> <input type="button" value="Export Data"/> <input type="button" value="Stats &amp; 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.
- Refer to <https://fsicu.com/professionals/benchmarking/> to look into obtaining a benchmarked report

## 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:	<a href="https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ">https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ</a>
Date paper survey completed:	<input type="text"/>
<p><b><i>We would like to hear your opinions about your family member's recent admission to the Intensive Care Unit (ICU).</i></b></p> <p>Your family member was a patient in this ICU. The questions that follow ask <b>YOU</b> about your family member's <b>most recent ICU admission</b>. 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 <b>your overall assessment</b> 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. <b>Please be assured that all responses are confidential.</b> The Doctors and Nurses who looked after your family member will not be able to identify your responses.</p>	

- 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:	<a href="https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ">https://ceru.hpcvl.queensu.ca/EDC/redcap_survey/surveys/?s=UgsNA4YQSJ</a>
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**