

Dartmouth CHF Quality Measure Development Project Recruitment Protocols for Qualitative Patient Focus Groups

Overview

We are developing new patient-reported outcome clinical quality measure for patients with heart failure. In this project, we are talking with patients in small groups to better understand how these conditions impact their lives and to determine what is most important to them. Each site will recruit 8-10 patients (for one focus group per site). We plan to schedule focus groups in April and May.

This document includes step-by-step instructions for recruiting patients to participate in focus groups – we include instructions for both onsite clinic staff as well as research coordinators at Dartmouth College.

Site Responsibilities

Task
1. Flag patients (30 patients)
2. Introduce patients to upcoming patient focus group
3. Share patient information

Recruitment by Research Team

Task
1. Initial contact with patient
2. Follow-up
3. Scheduling arrangements for focus group
4. Confirmation
5. Reminder (by phone or letter)

Site Responsibilities

Step 1: Flag Patients

Clinical staff will flag approximately 40 patients who fit the criteria below. Staff will identify current, active patients. Our goal is that the focus group participants will accurately reflect the typical patient population treated. All patients must be 65 years or older to participate and must be able to speak English.

Selection Criteria for Heart Failure

For patients with heart failure, the following must be met:

1. Diagnosed with active heart failure
2. Age 65 years or older
3. The patient cannot have had a heart transplant or LVAD

4. NYHA Class I (10% of patients); II/III (80% of patients); IV (10% of patients)

Level of Effort

- This step should take no more than 3 hours to complete. Any clinical staff member familiar with the selection criteria and the site’s EHR system can complete this step.

Step 2: Introduce Patients to the Upcoming Patient Focus Group

After flagging patients, clinic staff will call the flagged patients to introduce the planned patient focus group and the Dartmouth team. This introduction fulfills HIPAA and IRB requirements—the purpose is to inform patients that their physician is collaborating with the Dartmouth team and that someone from that team may be in touch about participating in a focus group. If the patient does not answer the phone, then you may leave a scripted voicemail, which also meets HIPAA and IRB requirements.

Level of Effort

- This step should take no more than 4 hours to complete. Any clinic staff member who normally interacts by phone with patients can complete this step. Sites often ask their scheduling staff to provide introductions.

If the patient indicates that he or she is not interested in being contacted, then remove him or her from the contact list. For those patients who indicate a willingness to be contacted, the following fields will be collected in an Excel spreadsheet to document patient introductions. This tracking spreadsheet will enable the research team to recruit patients into the patient focus group.

Header	Definition
First Name	First name of patient
Last Name	Last name of patient
Phone Number	Phone number of patient (XXX-XXX-XXXX)
Address	Patient address
Gender	Gender of patient
Age	Age of patient
NYHA classification	NYHA classification for stage of active heart failure (I, II, III, IV)
Provider Name	Name of cardiologist
Staff Person	Name of staff member who made introduction
Date of Introduction	Date when clinic staff made contact
Connected?	Yes, No, or Voicemail
Notes/Questions	Include any notes or questions that were asked by patient

Call Script

Hello, this is [insert caller’s name] from Dr. [insert name]’s office. Dr. [insert name] has partnered with researchers from Dartmouth College on an important project. They are talking to patients to understand how heart failure affects the lives of patients like you

and what is most important for you to be able to change. Someone from the research team may contact you soon about participating. Your participation is voluntary and will not affect your care. If you have any questions, you may ask the research team when they call. Thank you very much for your time.

Step 3: Share Patient Information

The final step is for clinic staff to share the information with the research team for patients whom have been contacted. To reiterate, patient information can only be shared following an introduction by the clinician staff, and such information must be transferred securely and meets each organization's (Dartmouth and site) secure data transfer protocols. Patient information will be permanently deleted after recruitment is completed and patient focus groups have been concluded.

Level of effort

- This step should take no more than 1 hour to complete

Recruitment by Research Coordinators

After the clinic staff has introduced patients to the research team, the research team will contact patients to recruit them into the focus group. The research team will attempt to contact patients a maximum of 3 times, using a staggered approach (described below).

Step 1: Initial Contact

The research team will contact up to 40 patients to request their participation in a focus group. They will also answer any questions patients may have regarding their involvement. If the patient is interested in participating, the research team will determine their availability for the scheduled focus group. Detailed scripts for recruiting patients into the focus group are below.

Level of effort

- Initial contact should take approximately 2-3 hours per 20 patients

The following call script should be used:

Hello this is [insert first name] and I am calling from Dartmouth College. A few days ago, someone from Dr. [insert name]'s office called you about a new project that Dr. [insert name] is doing with us. I am calling to tell you more about this project. We want to learn about patients' experiences with heart failure. We are looking for patient volunteers to talk with us about their condition. Participation is voluntary and your decision will not affect the care you receive. Are you interested in hearing more?

If NO, thank the person for his/her time and politely end call.

If YES, proceed to next paragraph.

Thank you. We are seeking input from patients with heart failure so that health care providers will have a better sense of what is most important to patients with this

condition. We plan to talk with patients about their experiences with the condition and its impact on their daily life. For example, we will ask you to think about what has changed the most since you learned of your condition. We will also ask you to describe something you'd like to fix related to having your condition. Your thoughts will be very valuable.

You will be joined by 7-9 other individuals with heart failure. The discussion will last about 2 hours and will be held at your doctor's office. You will not have to answer any questions that you do not want to answer. Refreshments will be provided. Your participation is voluntary.

Are you interested in participating?

If NO, thank the person for his/her time and politely end call.

If YES, proceed to next paragraph.

Thank you for your interest. We look forward to talking with you. We plan to have the group discussions on [insert date and time] at [insert clinic site]. Are you available on this date/time?

If YES, record availability and proceed to paragraph (A)

If NO, proceed to the paragraph (B)

A: Thank you very much for your time and interest. We will be in touch within the next two weeks to confirm the date and time of our group discussion and to provide any information you will need. Please try to keep that time available.

Proceed to (C)

B: We appreciate your interest. Unfortunately, based on the date and time it does not seem like we will be able to talk with you while we are at your doctor's office.

C: At this time, do you have any questions?

If the individual does not answer the telephone, the following voicemail should be left:

Hello this is [insert first name] and I am calling from Dartmouth College. A few days ago, someone from Dr. [insert name]'s office called you about a new project that Dr. [insert name] is doing with us. I am calling to tell you more about this project. We want to learn about patients' experiences with heart failure. We are looking for patient volunteers to talk with us about their condition. Participation is voluntary and your decision will not affect the care you receive. We will call back later this week. Thank you.

Step 2: Follow-up

Follow-up calls will be made to all individuals that were not reached during Step 1.

Level of Effort

- 8 hours per site

Use the script that was used for the initial outreach, with the following modifications:

- The first line should read, “Hello, my name is (Insert Name) and I am following up on a message I left earlier this week.”
- For voicemails, the last sentence should read, “This is our final message and we apologize for any inconvenience.”

Step 3: Scheduling

As described, the research team will set the date and time for each focus group prior to conducting any outreach with eligible patients. The research team will determine the availability of interested patients during Steps 1-3. Based on this information, the research team will assemble a list of interested patients, aiming for 10-12 patients per focus group.

Step 4: Confirmation

The research team will follow-up with interested persons to confirm their availability and provide additional information regarding their participation. Confirmation of participation will occur by phone approximately one week prior to the focus group.

The following script should be used:

Hello, this is [insert first name] and I am calling from Dartmouth College. We spoke two weeks ago about participating in a group discussion regarding how heart failure impacts your life. Ok, we have arranged for you to talk with a member of our team on [insert date/time]. Does that time still work?

If YES, proceed to next paragraph (A), (C) and (D)

If NO, proceed to paragraph (B)

B: We appreciate your interest. Unfortunately, it does not seem like we will be able to chat with you while we are at your doctor's office.

C: Great! I have information and instruction for that day. You will be joined by 7-9 other individuals with heart failure. The group conversation will last about 2 hours. Light refreshments will be provided. The discussion will be held at your doctor's office [insert site-specific directions]. Do you have any questions?

D: Thank you very much. We look forward to speaking with you. If you have any questions, please call a member of our team at 603-650-6693.

If the person does not answer the phone, the following voicemail should be left:

Hello, this is [insert first name] and I am calling from Dartmouth College. We spoke two weeks ago about participating in a group discussion on how heart failure may affect your life. This will be our last message. Thank you very much for your time and interest.

Recruitment Tracking by Research Team

The following should be documented for each patient that is flagged by clinic staff:

Header	Definition
Patient First Name*	Patient first name
Patient Last Name*	Patient last name
Date of Clinic Introduction*	Date which clinic staff made introduction
Connected? *	Response options include: Y/N/Voicemail
Date of Data Transfer	Date which patient information was shared
Research Team recruiter	Name of researcher responsible for recruitment
Date of Initial Contact	Date of initial contact by research team
Connected?	Response options include: Y/N/Voicemail
Outcome of Initial Contact**	Outcome of initial contact
Availability for Focus Group	Is patient available for focus group? Yes or No
Date of Follow-up (Intended)	Date on which follow-up should occur
Date of Follow-up (Actual)	Date on which follow-up occurred
Connected?	Response options include: Y/N/Voicemail
Outcome of Follow-up**	Outcome of follow-up
Date of Scheduled Focus Group	Date on which participant is scheduled to attend
Date of Confirmation Call (Intended)	Date on which confirmation call should occur
Date of Confirmation Call (Actual)	Date on which confirmation call occurred
Confirmed for Focus Group	Y = Indicator of confirmation for focus group

Note: Not all fields are applicable for all patients. If a field is not applicable, leave blank.

* These fields should be pulled directly from information that was given by clinic staff

** Response options include: Declined, Interested, Alternate List, No Contact