# CMC CoIIN Family Focus Group Guide: \_\_\_\_State Team Onsite Support Visit 2020

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| --- | --- |
| Date/Time |  |
| Facilitator |  |
| TA Support/Note Takers |  |
| Location |  |

**Facilitation Guide**

Prior to focus group – distribute electronically:

* Zoom access information (call-in phone number and computer link)
* One-page instructions for using Zoom (including Zoom app)
* One-page overview of CoIIN project
* One-page overview of state team’s project

BU team: create a welcome slide, and one with the following ground rules:

* + - Be honest about your opinions, ideas and feelings
    - Be respectful of others’, even if you don’t agree with them
    - Make time for others to talk, if you tend to talk a lot in group settings
    - Try something new and talk more, if you tend to be quieter in group settings

Show while focus group is going on

**Virtual group** **(settle in – 10 minutes)**

* 8-10 participants max per focus group; 2 hour duration
* Facilitators are the only additional attendees, each with their own laptop
* Please do NOT share this guide with participants ahead of time; focus group themes best emerge from spontaneous responses that allow the most salient considerations to arise
* The CMC CoIIN’s Zoom platform is available for the virtual meeting – let the BU team know at least 3 days in advance so we can schedule the meeting and get you the log-in information and “user instructions” to distribute to participants
* BU can test Zoom with participants ahead of time to ensure the technology will work
* BU will also conduct a test with the family leader who is facilitating the group – this should be scheduled at least a day ahead of time
* Before the meeting, BU will provide basic instructions to participants for using Zoom, reviewed in the first 5 minutes of the virtual meeting with participants.
* Participants will need a webcam preferably
* Participants can utilize Zoom on their cell phone – BU will include instructions for downloading the app along with the log-in information – state teams will distribute
* BU staff will send paperwork to fill out ahead of time by email for family leader facilitator honorarium of $200
* Be mindful of time as you facilitate the discussion (notetaker will help with this)
* Participants will need to complete the 2020 Focus Group Participant Stipend Form located on Box and email to Ben at [bplant@bu.edu](mailto:bplant@bu.edu)
  + If the participant does not have the technology to complete the form virtually, the facilitator can send the participant name and address in their place. (*This is a COVID-19 work around. Please confirm this still applies to your team if you are reading this post-pandemic.*)

**FACILIATOR TIPS: Please see** [**Focus Groups – Facilitator Tips**](https://cmccoiin.box.com/s/mj1fm3blt8d5fah1z5bh53s4fpnfuncw) **on Box**

**Two Essential Techniques: The Pause and the Probe**

Moderators of group discussions should be familiar with two essential techniques: the five-second pause and the probe. Both techniques are easy to use and helpful in drawing additional information from group participants. The five-second pause is often used after a participant comment. This short pause often prompts additional points of view or agreement with the previously mentioned position. There is a tendency for novice moderators to talk too much or to move too quickly from one topic to another, usually because they feel uncomfortable with silence. Often the short pause will elicit additional points of view, especially when coupled with eye contact from the moderator. Practice the five-second pause on family, friends, and coworkers. It allows you to become comfortable with this technique.

The second essential technique is the probe-the request for additional information. In most conversations and group discussions, there is a tendency for people to make vague comments that could have multiple meanings or to say "I agree." When this occurs, the probe is an effective technique to elicit additional information. Typically, probing involves comments such as the following:

* **Would you explain further?**
* **Would you give me an example of what you mean?**
* **Would you say more?**
* **Tell us more.**
* **Say more.**
* **Is there anything else?**
* **Please describe what you mean.**
* **I don't understand.**

***Fostering Differing Points of View***

Participants may need to be reminded of the value of differing points of view. The introduction provides the first suggestion that all points of view are needed and wanted. A second reminder is helpful if the moderator senses that participants are simply "echoing" the same concept. After several echoes on the same idea, the moderator might ask:

* **Does anyone see it differently?**
* **Has anyone had a different experience?**
* **Are there other points of view?**

*Excerpted from:*

Focus Groups, 3rd Ed., A Practical Guide for Applied Research

By Richard A. Krueger & Mary Anne Casey

Sage Publications, 2000

**START**

**Review basic Zoom instructions using screen share (chatbox monitor – 5 minutes)**

* Syncing phone and video - demonstrate
* Chat box – show where it is
* How to mute phone and computer lines – DON’T USE BOTH; if you’ve called in, use the mute button on the computer screen to avoid feedback (just turning down your speaker volume might not be enough)

**SCRIPT (15 minutes; includes introductions – begin recording and notetaking)**

*Thank you all for taking time out of your busy lives to be with us [today/tonight]. My name is [name] and I am [role on state team].*

*I’m part of the team that’s working with Boston University on a 10-state quality improvement project. The [site] here in [state] is part of that 10-state network.*

*A quality improvement project is different than a research project. In quality improvement, many small changes are made to the way things are done, in the hope that those changes make things work better in some way. Two of the things we’re trying to make better as part of our project is the quality of life for children with medical complexity and the well-being of their families.*

*We have had to figure out ways to measure whether we’re making things better, and if we are, how. We created a family survey that asks a couple of questions about child quality of life and family well-being, You may be asked to fill out this survey at some point. The family leaders on our team who helped us design it told us we needed to know more about these topics than just yes or no questions on a survey. We need to hear details about feelings and experiences from families directly.*

*We agree that no one knows better than families themselves what is important in each of these topic areas and that’s what we’re here to learn from you. We’ll take what you tell us and summarize it for the state team so they can incorporate it into planning the changes they make as part of their project.*

*If you’d like to learn more about the [site location]’s project, there is a handout about it available. The handout has the contact name and number for a [site] staff person who would be happy to answer any further questions you might have.*

*I’ll be leading today’s/this evening’s family focus group, along with my colleague [name] from Boston University. She’ll be taking notes while we talk, and will help me keep track of time. She may interrupt us at any point during the focus group to ask you to repeat or clarify something – we thank you in advance for your patience if that happens.*

*My colleague [name] from BU will be monitoring the chat box for any technical problems you might have.*

*In addition to [BU staff] taking notes, we are also recording [today’s/tonight’s] focus group discussion. We’re doing this so that we can capture everything you say exactly as you say it. You are giving us the gift of your time and expertise, and we value both very much. When we’re finished using the recording to add to or correct our written notes, we’ll be destroying it.*

*We are pleased to be able to offer you $50 [check, gift card, etc.] as a token of our appreciation. The required paperwork has been posted on Box, our shared online workspace. There will be a link in the chat box to it at the end of the focus group. If you’d prefer we email it to you, just let us know after the focus group.*

*Please fill the paperwork out and return it to Ben Plant at Boston University by [due date]. Ben’s postal mail and email addresses are on the request form. If you do not have the technology to complete the form virtually, our team can send your name and address in its place. If you are in need of this work around because of COVID-19, please let us know after the group concludes.*

*We will be sharing written highlights of the discussion with the [STATE] team but any identifying information like your name, your child’s name or your child’s diagnosis will be removed first. However, anything comes up that makes us worry about your safety or your child’s, we may have to speak with your team about it. We will, of course, talk with you first.*

***Ground Rules***

*Just to make sure we’re all on the same page, we would like to go over some basic guidelines for [today’s/tonight’s] focus group.*

*First, we know that it’s not always easy to stay focused during a virtual discussion; it’s easy for me to be tempted by distractions when I’m listening on my computer. Please try to limit your use of the Internet, texting or email while the focus group is in session. And please don’t hesitate to let us know if you run into any technical problems using the chat box; [BU staff] will do their best to help you.*

*The topics we’ll be discussing are deeply personal and people may have strong feelings about them. Each child is an individual and each family is unique, so there’s no one “right” way of doing things. Please be honest when sharing your experiences, ideas and feelings and listen with an open heart and mind to others.*

*It’s important in a focus group for the participants to be able to hear each other’s ideas and opinions, so they can react to them with their own. If you have technical trouble, or if you’re having difficulty getting into the discussion, please use the chat box to alert [BU staff]. She’ll do her best to help you. We do encourage you though, to give your discussion input verbally instead of in the chat box so others can hear and learn from you.*

*Our time together is unfortunately limited, and we want to make sure we hear from as many of you as possible in as many ways as possible. Please try to balance your time talking with that of others in the group – if you think you’ve been talking a lot, try to step back a little and give others the floor; if you’ve been quiet, please take a chance and speak up – we really want to hear from you. [Notetaker name] or I might try to help by asking you to step back or step forward; please don’t feel criticized or put on the spot if that happens.*

*Before we jump into [today’s/tonight’s] discussion, does anyone have any questions about what I just went over?*

**Start of focus group (begin notetaking)**

*We have two overarching topics that we want to learn from you about over the next hour: Child Quality of Life and Family Well-Being. As I mentioned earlier, no one knows better than families what’s important in these two areas and that’s what we’re here to learn from you about [today/tonight].*

*The questions we’re going to ask [today/tonight] were developed by a committee of families of children with medical complexity from across the country. We are grateful to them for their time and contributions to this work.*

*Okay, time for me to stop talking and let’s introduce ourselves to one another. We’re going to go around now and say our first names, our child with medical complexity’s age(s) and one thing, in ten words or less, about what brings you joy in parenting your child. As I mentioned earlier, my name is [name], my son/daughter is [age] and one thing that brings me joy in being his/her mom/dad is [ten words or less].*

*Okay, now we’re going to jump into some questions about child quality of life. If at any point you have a question about what is meant by a certain word or phrase, please don’t hesitate to let us know. If you’re wondering, other people probably are, too.*

**Child Quality of Life Questions (30 minutes)**

*While children with medical complexity have a lot of attention focused on their special health care needs, their quality of life and its connection to their health care is also important. What does quality of life mean? It’s different for everyone, and it might look very different than what people who don’t know your child might assume for him or her. Being as free from pain as possible, being able to do things he/she enjoys, having people who are important to him/her in his/her life, and being seen as an individual (not a diagnosis, a “case” or just a patient) are some examples of what the families who helped us create these questions had in mind.*

*So, here’s our first question:*

1. What is important to you and/or your child in terms of your child’s quality of life?
   1. [*If attendees seems to be having trouble conceptualizing a good QoL, shift to asking about what they don’t want for their child’s QoL*]
   2. [What can your child’s care team do to help with what’s important to you and/or your child?
2. Does anyone on the care team ask what you and your child’s hopes, dreams and goals for your child’s life are?
   1. [What do they do with this information?]

**Family Well-Being Questions (30 minutes)**

*The families who helped us create these questions told us that their family’s well-being is critical to their child’s quality of life – one cannot grow and thrive without the other. Some of the things that make up well-being for families raising children with medical complexity include having their child be as free from pain as possible, feeling competent and comfortable providing medical care, freedom from financial hardship, living in a community they feel part of, being able to have fun as a family and being able to take a break from caregiving when needed.*

1. What are the most important parts of the overall well-being of your family?
   1. [*If attendees seems to be having trouble conceptualizing a good QoL, shift to asking about what they don’t want for their child’s QoL*]
   2. [How can your child’s care team provide care in a way that helps support your family’s well-being?]
2. What are some of the ways that your family adapts amidst the challenges and joys of caring for your child with medical complexity?
   1. [What can the care team do to foster and support your family’s well-being?]
3. In what ways has your child’s care team addressed what matters most to you in terms of your family’s well-being?
   1. [Can you give us an example of what that looks like?]
   2. [How is this considered in the care process?]
   3. [Are there other ways you’d like to see this addressed?]

**\*\*If Time Remains\*\***

**Once all other questions have been covered,**

**feel free to ask any supplemental questions your team may have, or choose from the supplemental question examples at the end of this document.**

**[5-10 Minutes To Wrap Up]**

*That was the last question that we have for you [today/tonight]. This discussion has given us a lot to think about, and take back to our work on improving care delivery for children with medical complexity. If you would like a copy of the highlights document we plan to share with the state team, please let us know. We’d be happy to send it to you. Thank you again for your time and expertise.*

BU chatbox monitor – post link to reimbursement request form on Box

**ADDENDUM**

**SUPPLEMENTAL QUESTION EXAMPLES** *- to consider once all other questions are covered; also feel free to develop your own team’s list*

**Child Quality of Life Supplemental Question Examples:**

What does a meaningful life look like for your child?

What does it mean for your child to be regarded and treated as a whole person?

What can your child’s care team do to better respect, value and treat your child as a whole person?

What can the care team do for your child to allow your child to be as independent as possible, as defined by you and your child?

**Family Well-being Supplemental Question Examples:**

Tell us what an ideal and satisfying week looks like for your family.

What does your family need in order to be well as a family unit while raising a child with medical complexity?

How are your family’s priorities to foster family well-being considered and addressed by your care team?

What else could be done?

*Acknowledgments*

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #UJ6MC32737: *Health Care Delivery System Innovations for Children with Medical Complexity* ($2,700,000 annually). This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsement be inferred, by HRSA, HHS or the U.S. government.

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Permission is given to use or adapt this focus group guide. We ask that you cite the *Health Care Delivery System Innovations for Children with Medical Complexity* project as the original authors.

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