Colbert Consent Decree

Quality of Life Survey
Baseline Surveys
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Part 1: The Quality of Life Survey

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Data is used to evaluate our success in meeting the needs of program participants, and also to identify changes needed to improve the program.

QOL surveys are an opportunity for us to learn from the individuals we are serving under Colbert, and it is their opportunity to give us the information we need to make our program and our care coordination responsive to them.

The QOL is a valuable tool for staff to use in their person–centered planning for community transitions.
QOL Key Measures

- The QOL survey asks for the **members’ perceptions and feelings** across seven key domains, providing an important means for them to communicate with you about their current:
  - Living situation
  - Ability to exercise choice and control
  - Accessibility to personal care
  - Treatment in terms of respect and dignity
  - Sense of being part of a larger community
  - Overall satisfaction with life
  - Health status
QOL Basics

- The QOL survey will be administered at:
  - **QOL:** Two to four weeks prior to actual community transition.
- All surveys are administered in the paper format.
- Information collected in the survey is confidential and HIPAA protected.
- Surveys must be kept and transmitted under HIPAA compliant secure procedures (secure fax transmission or password-protected email attachment or Colbert email).
- Completed surveys must be faxed or emailed to UIC–CON for processing within 2 weeks of completion.
- UIC–CON Timothy Crowley (Email [Ticrowle@Illinois.edu](mailto:Ticrowle@Illinois.edu) or fax: 217–586–6059)
Timing is KEY (Baseline Surveys)

- The QOL baseline survey must be administered two to four weeks prior to the scheduled transition date.

- The survey must be conducted prior to transition in order to reflect accurately each individual’s personal perceptions and experiences while he or she is still living in the nursing facility.

- The baseline survey provides critically-important information about participants’ experiences and is an excellent opportunity for transition coordinators to learn more about a participant, as an aid to person-centered planning, and to help make a smoother community transition.
INFORMED CONSENT (IC): A signed/dated Informed Consent must be provided to the Colbert Program & UIC–CON

BASELINE QOL: Administer two to four weeks prior to the scheduled transition date. If the transition is significantly delayed (over 3 months) for any reason, you may need to re-administer QOL Baseline, especially if the participant’s circumstances have changed
Part 2: Interview Guidelines

- Some Basics
- Assisted/Proxy Interviews
- Before You Begin the Survey
- Administering the Survey
- Closing the Survey
- Critical Issues: Submitting the Survey
Your Role

- Your goal is to gather information only: requests for assistance or complaints about existing services should be directed to appropriate authorities.
  - *NOTE: Explain to the participant that you may be required by law to report incidents of neglect or abuse. (This is also stated in the opening script.)*

- If you have any reason to believe that the participant is a potential danger to him/herself or to others, postpone the survey and discuss your concerns with your supervisor.

- Take the time necessary to ensure the participant is comfortable with you, as well as with the survey process and its purpose before proceeding. Answer all questions honestly and be sure to use the **FAQ handout** to prepare.

- Be sensitive to the participant’s physical, emotional, and cognitive state. Participants may tire easily and may become distracted, confused, or frustrated. Take breaks if needed, or if necessary, end the survey and reschedule a time to complete it later.
Because individuals are always the best judge of their own experiences, proxy or assisted interviews should only take place when it is not at all possible for the participant to respond for himself or herself (Proxy handout).

Consider whether an accommodation such as taking breaks or a different setting (fewer distractions), would enable the participant to take the survey without an assistant or proxy.

If an assisted or proxy interview is necessary, ask if there is someone the participant would like to have assist or act as proxy. *Whenever possible, the participant should always be present, if using an assistant or even when using a proxy.*
Proxy or Assisted Interviews (2/2)

- Be aware of potential conflicts of interest in identifying individuals to act as an assistant or proxy—**for example, using provider staff as proxies or assistants is NOT appropriate.**

- Ideally, the assistant or proxy would be a friend or family member who is very knowledgeable about the participant and able to answer on his/her behalf as he/she would answer.

- Clearly instruct the assistant or the proxy that the purpose of the survey is to obtain the **participant’s** point of view and not that of the assistant or proxy. To reinforce this, please change the wording of questions as necessary by substituting the participant’s name for “you” and “your.”

- Please note name, contact number, and relationship of proxy/assistant to participant on the final page of the survey.
Before You Begin the Survey

- Before beginning, talk to the participant about the survey’s purpose and importance, letting him or her know that we appreciate his or her participation.

- Be honest and accurate in responding to any questions about the survey (FAQ Handout) and be certain to explain confidentiality and its limits in regard to abuse and/or neglect concerns.

- Reassure the participant that there are no “correct” answers. “Best guesses” and “Don’t know” are perfectly fine, and they may refuse to answer any question. (PROXY/ASSISTANT: must NOT “guess.” He/she should answer “Don’t Know” if not certain how the participant would respond, if he/she could respond.)

- Emphasize that responses to questions (including refusals) will not in any way whatsoever affect his or her care, benefits, or participation in this program.
Administering the Survey

- Inform the participant/proxy/assistant that you must read the question exactly as it is written in the survey, and tell him/her that, when you ask a question, you will also read the answers.

- Ask all the questions, *carefully following the skip patterns*, required for whichever version of the QOL you administer. Do not leave any required questions blank. If there is no answer, not even a refusal, write “no response”.

- If the participant/proxy/assistant has difficulty understanding the question, use the prompts in the annotated survey for help, or ask the individual to tell you in his/her own words what he/she thinks you asked.

- Be certain to record all answers exactly as given by the participant/proxy/assistant. Please do not interpret or “lead” the participant to a particular response. If an answer is vague or unclear, try using probes provided in the annotated survey version.
Closing the Interview

- At the end of the interview, be certain to thank the participant/proxy/assistant for his or her participation.

- If the participant/proxy/assistant has any additional concerns or questions about the survey, take the time to answer or reassure him or her that you will follow up later, if needed.

- Leave your contact information so that the participant/proxy/assistant can contact you after the interview, if he or she has additional questions about the survey.

- Once the survey is completed, however, the participant/proxy/assistant may not contact you to change his/her answers.
Critical Issues: Survey Submission

- Information in the QOL survey is time-sensitive and must be sent to UIC–CON within two weeks of its completion.

- Please forward your completed surveys immediately by secure fax transmission *(please alert Timothy by email or phone that you are faxing a survey)* or a password-protected scan via secure email transmission to:

  Timothy Crowley  
  Institute for Health Care Innovation  
  UIC College of Nursing  
  email: ticrowle@illinois.edu  
  phone: (217) 586–6039  
  fax: (217) 586–6059
Part III: Review Survey Instrument

- The Question–by–Question Overview
- Coversheet: Respondent Information Section
- Begin the Survey: Introductory Script
- Review of Survey Modules 1 through 7
- End the Survey: Complete Closeout Section
- Critical Issues: The Survey
The “QxQ Overview” provides an explanation of each question, identifies the skip patterns, gives information about how to clarify a question, if requested by the participant, and includes possible probes where needed.
Coversheet: Respondent Information

- Please **print clearly** and carefully so that we can transcribe this section accurately, and please be certain you have the correct RIN. (Please do not include the SSN or the case number; we can only use the RIN.)

- The date area on the coversheet is to be used **ONLY** to record the participant’s death. The date you administer the baseline survey is recorded only in the “Closeout” section on the last page.
This script must be read exactly as it appears in the survey. Simply fill in your name and affiliation where needed in that introductory script.

Please be certain to write your name and the name of your agency in the spaces provided, so that when we receive the survey from you we can properly code and enter the survey data.

If you want, you can preface reading this script by telling the participant something along these lines: “I know this may sound silly that I am reading this, but it is important that, every time I do a survey, I must begin the exact same way.”
Module 1: Living Situation

- At the beginning of each new module, it may be helpful to let the participant know you are beginning a new section. For example, here you could say something like:
  - “We will now begin the first part of the survey. This section asks for your feelings about your current living situation here at the nursing home.”

- **ALL SURVEYS:** Please watch the skip patterns in this section for Q1 and Q5 that will affect which follow-up question you are required to ask.

- **BASELINE ONLY:** Q2 should always be answered “Yes”, since the person is in an ICF/DD or SODC setting, or a Nursing Facility (NF).
In Module 2, it may be a bit confusing for the participant to understand just what we mean by “choice and control”. Reviewing the annotated version of the survey gives you some additional information about each section of the survey and its purpose, that you can share with the participant before you begin this module.

**ALL SURVEYS:** No separate instructions.

**BASELINE ONLY:** DO NOT ask Q13/Q13a. (Cross them out). These are asked “After Transition ONLY” when you administer the Year 1 and Year 2 surveys.
Module 3: Access to Personal Care

- **Question 14** is critically important, not only for Module 3 but also for how you will need to handle Module 4 as well.

- The participant’s answer to Q14 is key here. Even if you are certain his/her answer does not reflect your knowledge of the current circumstances in the facility setting, it is always the participant’s perception that matters!

- **ALL SURVEYS:** There are very extensive skip patterns in Module 3 for Q14, Q15, Q16, Q17, Q18 that will determine which follow-up question you are required to ask.

- **BASELINE ONLY:** DO NOT ask Q19/Q19a/Q19b, Q20, Q21/Q21a (Cross them out). These are asked “After Transition ONLY” in administering Year 1/Year 2 surveys.
Before you begin this module you must **review the answer to Q14 in Module 3**. That answer determines whether you have to administer Module 4 or if you will have to skip Module 4.

- If the answer to Question 14 in Module 3 was “No”, “Don’t Know” or “Refused,” then you will **skip Module 4 entirely** and go directly to Q27 at the beginning of Module 5.
- If the answer to Q14 in Module 3 was “Yes,” you must **administer Module 4 in its entirety**.

**ALL SURVEYS:** There are very extensive **skip patterns** in Module 4 for Q22, Q23, Q24, Q25, Q26 that will affect which follow-up question you are required to ask.

**BASELINE ONLY:** No separate instructions.
Module 5: Community Integration

- You may want to “check in” with the participant by letting them know you are more than halfway to end of the survey.

- **ALL SURVEYS:** There are very extensive skip patterns in Module 5 for Q27, Q28, Q29, Q30 that will affect which follow-up question you are required to ask. Please be certain to ask Q33, Q34, Q35, and Q36 at the end of this module!

- **BASELINE ONLY:** Do NOT ask Q31/Q31a or Q32/Q32a (Cross them out). These are asked “After Transition ONLY” in administering Year 1/Year 2 surveys.
Module 6: Satisfaction

- Again, alert the participant that you are beginning a new section and also let him/her know that there is only one additional section after this one in the survey and you are “almost done!”

- **ALL SURVEYS:** There are very extensive skip patterns in Module 6 for both Q37 and Q38 that will affect which follow-up question you are required to ask.
  - If you ask the wrong follow-up question here (which happens frequently with these questions), we are unable to use the answers at all.

- **BASELINE ONLY:** No separate instructions.
As you begin this section, you may want to let the participant know that this is the last part of the survey. You do not want to rush them through this (or any) section, but checking in to let him or her know where you are in the survey can help them stay focused and reassure them that the end is in sight.

Note that the questions in this section are designed to give you additional information about the participant’s physical, mental, and emotional well-being. Be prepared for surprises or for, “red flags” that you will want to handle appropriately.

**ALL SURVEYS:** There are very extensive skip patterns in Module 7 for Q39, Q40, Q41 that will affect which follow-up question you are required to ask.

**BASELINE ONLY:** No separate instructions.
Let the participant know that you are at the end of the survey and need to ask for some final information.

Please read Question 42 exactly as it is written. This is information we need to follow up with the Year 1 and Year 2 surveys in particular.

Obtain (Print clearly.) as much contact information as possible, especially the name and phone number, so UIC–CON can conduct follow-up QOLS

Please be certain to answer Q43; this is critically-important information that determines how the collected data is handled for analysis; clearly print the date of the survey.
Critical Issues: Survey Structure

- **Skip Patterns Matter**: If you do not follow the skip pattern correctly, it limits the usability of the information you gather—not only for program evaluation purposes, but also for learning from your MFP participant.

- **FOR BASELINE ONLY– Ignore “After Transition Only” Questions**: It may help you to cross through them on your paper copy of the survey as a reminder to not ask them for the baseline survey.

- **Practice & Use the Annotated Survey**: Practice administering the survey with a colleague to become familiar with the structure of the survey before you administer it the first few times, or after a long period of not conducting the survey.

- **Participants** may find it helpful and less stressful if you guide them through the survey and give them breaks as needed.
The Quality of Life baseline and follow up surveys are a critically important part of the Colbert Consent Decree, and we appreciate the time you have taken to complete this training.

If you have questions at any point about administering the Quality of Life survey, or have other QOL related questions, please contact ticrowle@illinois.edu and he will be happy to assist.

We are also very interested in learning from you if you experience any particular problems or challenges in administering the QOL.