

Scenarios: Transition between Participant to Proxy

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Scenario #1: Proxy is hesitant to answer questions on behalf of the participant:

- Continue to assure the LAR/proxy that we will engage the participant in some interviews, but that we also need someone who knows the participant well to answer some questions from their perspective. *In this scenario, an interviewer may say: "As our study is getting older and so our participants, we feel it is best to also gather additional information from those that know the participants well".*
- If there is a sense that the proxy is in denial about their loved one's cognitive status or perception that cognitive function is not impaired. *In this scenario an interviewer may say, "I noticed during my phone call with Mrs. ___ that she had difficulty with some of the questions. She gave me permission to talk to you/asked me to call you to help with this section of the interview. Would you mind answering some questions on her behalf?"*

Scenario #2: Participant not wanting to provide consent for a LAR:

- Consider asking questions of participants with a follow-up that you would also like to talk with someone who knows them well, either a proxy/informant/LAR
- Flag interview as participant completed, proxy informed

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Scenario #3: We have 2 participants in which the AFU dementia reflects as not being impaired yet both of them meet LAR requirements, when speaking with the LARs and even conducting an ADS they are saying the participants are able to participate on their own behalf (one LAR even stated that there has been no official dx made by health provider or professional). In this scenario when sIRB is obtained from LAR does that mean that all following interviews should be through the LAR or are we able to still conduct interviews with the participants? If so, does this make the data collected to be considered inaccurate if we continue to collect data from someone labeled as technically "Requiring a LAR?"

A LAR is required only for consent purposes for the sIRB, and not necessarily to do the interviews. Even if a participant requires a LAR, they can still do the interview on their own. You, or the participant, may determine that a proxy or informant is needed to help with the interview questions and that is certainly okay but is not necessarily required.

In these two cases when the participant meets the LAR requirement, has the LAR provided consent yet? If yes, then you can proceed with the interview with the participant. If the LAR has not consented yet, then the interview should not be done with the participant. When a LAR is required, it does not mean that the entirety of the interview needs to be done with the LAR, but rather that the interview cannot proceed without consent from the LAR first.

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Scenario #4: A follow-up interview was conducted with the participant since they did not require a LAR based on the SIS nor did the interviewers feel the participant was impaired in speaking with them. However, the participant's proxy called the interviewers and indicated that the participant does have some cognitive impairment and that the participant would not be able to provide accurate responses to the questions. The proxy is the participant's daughter that lives with them. In this scenario, where the participant is not impaired based on our ARIC assessments, do we move forward with the interview with the participant only OR should we also consider conducting the interview with the proxy/LAR to confirm participant responses? *In this scenario, the interviewer has spoken with the participant before the proxy. Proceed with interviewing the participant, but also ask permission to speak with the daughter. For example, "Thank you for answering these questions. We often also ask someone who knows you well to answer similar questions. Would it be OK if we spoke to..."*

In the above scenario, if an interviewer speaks to a proxy before having a chance to conduct an interview with the participant, we would still like you to complete the interview with the participant. In this case, an interviewer can say to the proxy: "For research purposes, it is helpful to also get input from the participant".

Please always use the notelog to indicate specific circumstances that might yield data collection on both a participant and proxy. If a participant is interviewed and then responses are confirmed/updated by the informant, in the same record in CDART, note that the confirmation took place. Instructions in CDART are as follows: "If the interview is done with the participant and the responses are confirmed or updated per a proxy/informant, record item 1 as 'A. Participant contacted, agreed to be interviewed' and add 'Confirmed with proxy/informant' in the notelog for item 1."

Scenario #5: ARIC spousal pair where the husband requires a LAR (and the proxy is the wife and also an ARIC participant), but the husband insists on doing the interview. The interviewers noted the challenge of having the proxy so close to the participant and also engaged with the study and are inquiring about how to handle the potential sensitivity of one person being both the proxy to an ARIC participant and an ARIC participant themselves. *We discussed the option of having the interviewers do the questionnaire with the impaired participant but also confirming responses by conducting the interview with the proxy/spouse. In doing so, they could call and ask the unimpaired proxy/spouse if there is a good time to speak with them in private so that they can feel comfortable to discuss their spouse's health. Interviewing the proxy as the best source for answers, but also interviewing the participant for their comfort seems appropriate. Asking the wife for a good time to call her would afford opportunity for her to respond honestly and without upsetting her husband.*