

ENROLLMENT

B. Decline enrollment in follow-up

What happens if the family declines enrollment?

If the family tells you they decline participation in the study, try to find out why they are declining. Since we are funded by NIH, we are required to ask you a reason why you don't want to participate. Also let the family know that if they ever change their mind in the future, or if they ever have any questions for us, please don't hesitate to call. Hold onto that letter just in case.

The reason, and date received is recorded on the follow-up sheet. The follow up sheet is then filed in the NEC/NOC Refusals binder. The information is also recorded in the NEC Recruitment table in the database.

If you have left messages for the family, and no calls have been returned, or if you have described the study to the family, and they have stated they'd like to think about it, but do not call back, and you are unable to reach them again, this is considered "passive refusal". This refusal reason is recorded as "Unknown, can't reach" AND "No response". Generally, this occurs after 3 phone calls for moderates, and 6 phone calls for high and NOC. At the time that the last call is made, give the family a deadline (5-7 days) to call you back.