

Sickle Cell Disease Quality of Life Project

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Synopsis:

General study design. The next phase of this research will employ qualitative research techniques (cognitive interviewing) to collect feedback on draft questionnaire items from persons affected by SCD. There will be up to 36 interviews conducted with people with SCD, with half conducted in Chapel Hill, NC, and half conducted at CHRCO. Testing will consist of two rounds. Therefore, each round will include up to 9 participants in order to have up to 18 at each site and 36 total. The participants will be heterogeneous with respect to gender, age, and education to the greatest extent possible.

Patient selection. Individuals will be recruited by local SCDAAs chapters in North Carolina. They will select participants from their clientele and will be responsible for providing as heterogeneous a population as possible. Interviewers from AIR will then travel to the local chapter locations and interview selected participants. At CHRCO, flyers will be posted to recruit participants. (Flyers are included as part of this package.) Other potential participants will be contacted by members of the project's local advisory group and by members of the research team and provided similar information about the study. Interested potential participants will be asked to phone an 800 number for further information about the study. The person answering the phone will determine eligibility in order to recruit as maximally heterogeneous a sample as possible.

Inclusion criteria. For the cognitive interviews, only people with sickle cell disease will be eligible to participate. In addition, participants must be at least 18 years old. As previously noted, we will try to recruit a mix of educational levels and of age groups.

Exclusion criteria. Anyone under the age of 18 and anyone who does not have sickle cell disease is not eligible. Since a written version of a questionnaire is being administered, individuals unable to read (because of literacy, visual, or cognitive problems) will not be eligible for participation.

Procedures. Interviews will be lead by a trained interviewer, who is knowledgeable about sickle cell disease. An interview guide and participant questionnaire will be submitted before testing begins. Cognitive interviews will be administered in person. Subjects will be reimbursed \$75 for their time