

### **Sickle Cell Disease Treatment Demonstration Program**

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**You are being asked to take part in a research study. This consent form tells you about the study and the type of information that will be asked of you. You can choose to take part in the study or not. If you choose to take part, you will need to sign this form.**

Your doctor/clinic is participating in a study conducted by RTI International. This project is funded by the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA). This project is taking place at four locations across the United States and about 400 adults and children will take part. The study is designed to learn about the medical and health care experiences of patients enrolled in the Sickle Cell Disease Treatment Demonstration program.

If you agree to be in this study, you will be asked to provide some information when you are first enrolled and again one year later. The questions regard your health and health care. It will take 30 to 45 minutes to complete the questions. You do not have to answer any questions you do not want to answer. No names will appear on the forms. If you decide to fill out the forms, you can stop at any time. If you decide that you will not take part in the study, it will not affect the health care you receive from this doctor/clinic.

[You may not be able answer all the questions we ask or we may need to verify what you told us. When that happens, we will need to check your medical record. The kinds of information we would be getting from your medical record would be things like the timing and number of hospital and medical visits and the kinds of treatments and vaccinations you have received.](#)

[By signing this form you give your provider \[INSERT NAME AND ADDRESS\] permission to release health information about you to RTI International. This authorization expires on September 30, 2010. You may revoke this authorization at any time by notifying \[NAME OF THE LOCAL SCDTDP\] in writing.](#)

There are no direct benefits to you for taking part in this study. By providing this information, you will help to answer questions about the sickle cell treatment model that we are studying. All of the information and comments that you share with us will remain private [to the extent allowed by law.](#)

If you have any questions, please ask us. If you have questions later, please call RTI at (301) 230-4677. If you have questions about your rights as a participant in research, call the RTI Institutional Review Board Chair at (xxx) xxx-xxxx.

I agree to participate in this research study.

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Name (print)

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Signature/Date

Adult Consent Form  
*Draft version - not reviewed by IRB.*