Attachment 8: Demographic Questionnaires

Table of Contents

Demographic Check-in Form for Parents/Caregivers	. 8 -3
Demographic Check-in Form for Patients	8-5
Demographic Check-in Form for Providers	8-7
Demographic Check-in Form for Information Technology (IT) Developers	8-9

ACTION Sickle Cell Disease Focus Groups Demographic Check-in Form Parents/Caregivers

Thank you for participating in the sickle cell disease focus group. Before we get started, we would like to ask you to confirm a couple of pieces of basic demographic information. Your responses to these questions and your input during our discussion today will remain confidential. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). This information will help us better understand the input we gather through the focus group. Thank you in advance for your time and participation.

How old are you?
Are you currently employed? ☐ Yes. If yes, what is your occupation? ☐ No
Please select the race/ethnicity category that best represents your family. Are you Hispanic or Latino/Latina? No Yes
What is your race? Please select one or more. American Indian/Native American or Alaskan Native Asian Native Hawaiian or Other Pacific Islander Black or African American White Other

4.	What is the gender of your child who has sickle cell disease?
	☐ Male
	☐ Female
5.	How would you rate your child's current health?
	☐ Excellent
	☐ Good
	☐ Fair
	□ Poor
6.	What is the health insurance status of your child?
	☐ Medicaid or public insurance
	☐ Commercial Insurance
	☐ Uninsured
	☐ Don't know/not sure
7.	Where does your child receive routine sickle cell care?

ACTION Sickle Cell Disease Focus Groups Demographic Check-in Form Patients

Thank you for participating in the sickle cell disease focus group. Before we get started, we would like to ask you to confirm a couple of pieces of basic demographic information. Your responses to these questions and your input during our discussion today will remain confidential. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). This information will help us better understand the input we gather through the focus group. Thank you in advance for your time and participation.

1.	How old are you?
2.	What grade in school are you currently in/going into?
3.	Please select the race/ethnicity category that best represents your family. Are you Hispanic or Latino/Latina? No Yes
	What is your race? Please select one or more.
	☐ American Indian/Native American or Alaskan Native
	☐ Asian
	☐ Native Hawaiian or Other Pacific Islander
	☐ Black or African American
	☐ White
	☐ Other

4.	What is your gender?
	☐ Male
	☐ Female
5.	Where do you receive routine sickle cell care?

ACTION Sickle Cell Disease Focus Groups Demographic Check-in Form Providers

Thank you for participating in the sickle cell disease focus group. Before we get started, we would like to ask you to confirm a couple of pieces of basic demographic information. Your responses to these questions and your input during our discussion today will remain confidential. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). This information will help us better understand the input we gather through the focus group. Thank you in advance for your time and participation.

1.	How old are you?
2.	Please select the race/ethnicity category that best represents your family.
	Are you Hispanic or Latino/Latina? No Yes
	What is your race? Please select one or more. American Indian/Native American or Alaskan Native Asian Native Hawaiian or Other Pacific Islander Black or African American White Other
3.	What is your gender? Male Female
1	What is your clinical specialty?

5.	How many years have you been practicing within this specialty?
6.	How would you characterize your practice? (select one)
	☐ Pediatric care
	☐ Adult care
	☐ Both
7.	How comfortable are you in using technology in health care (such as electronic health records)?
	☐ Not comfortable
	☐ Somewhat comfortable
	☐ Very comfortable
	☐ Expert

ACTION Sickle Cell Disease Focus Groups Demographic Check-in Form Information Technology (IT) Developers

Thank you for participating in the sickle cell disease focus group. Before we get started, we would like to ask you to confirm a couple of pieces of basic demographic information. Your responses to these questions and your input during our discussion today will remain confidential. Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). This information will help us better understand the input we gather through the focus group. Thank you in advance for your time and participation.

1.	What is your area of expertise within IT/HIT?
2.	Do you have experience building HIT tools for patients with chronic conditions, such as
	sickle cell, to help manage their care? If yes, please explain briefly.
3.	What type of organization do you work for? (e.g. IT company, university, etc.) ?

4.	What training or education did you receive for your current role in technology? (include degrees with major and any specific training relevant to HIT)
5.	Do you have any potential conflicts of interest with regards to recommendations for the development of an IT-enabled tool for care transitions for patients with sickle cell disease? (circle one)
	Yes No
	If yes, please explain: