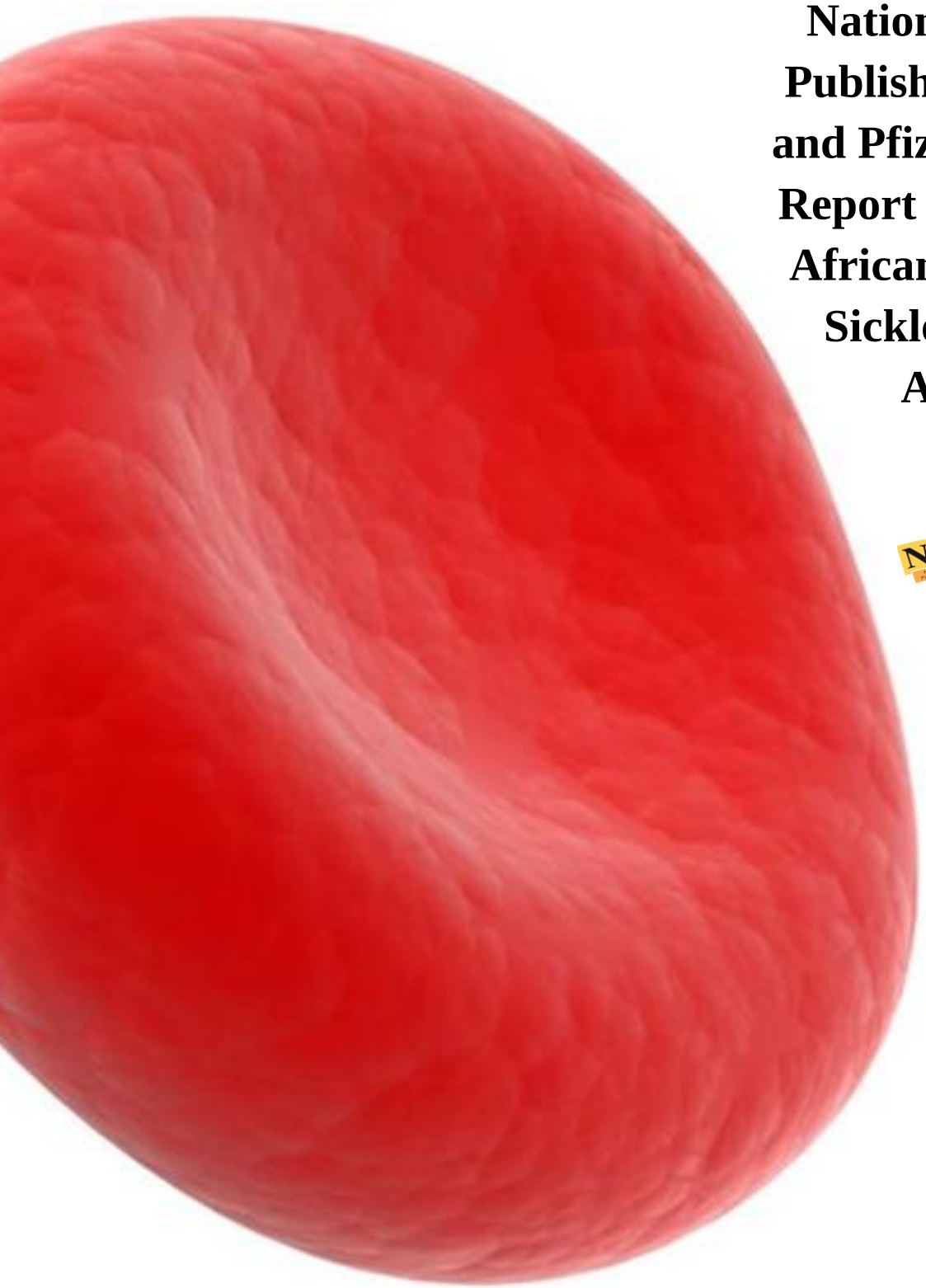

National Newspaper Publishers Association and Pfizer Rare Disease Report National Poll of African Americans on Sickle Cell Disease Awareness

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INTRODUCTION

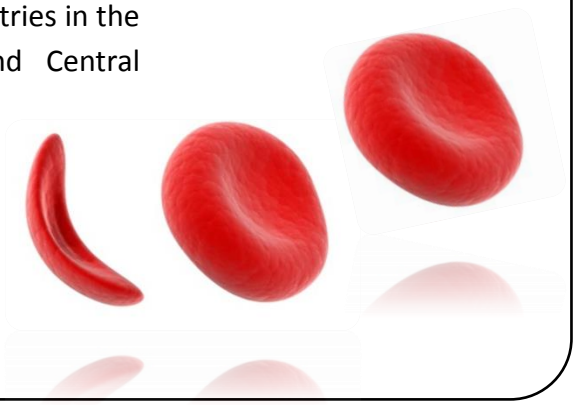
Awareness and understanding of sickle cell disease (SCD) and its treatment have not received adequate attention despite its significance and magnitude in the United States, and more specifically, within the African American community. While SCD is hardly unique to African Americans, its historic and harmful proliferation throughout the community makes the treatment of it, and information about it, particularly important to this community.

Unfortunately, very little information is available regarding how African Americans learn and receive information about SCD and the treatments associated with this condition. While substantial progress has been made in the availability of medications and effectiveness in treating the disease, more information is needed to understand how individuals most likely affected by it acquire, interpret, and communicate relevant information. This survey research sought to address that need by polling more than 700 African Americans across the United States to assess their concerns, level of knowledge, modes of communication, feelings about and attitudes toward SCD.

BACKGROUND

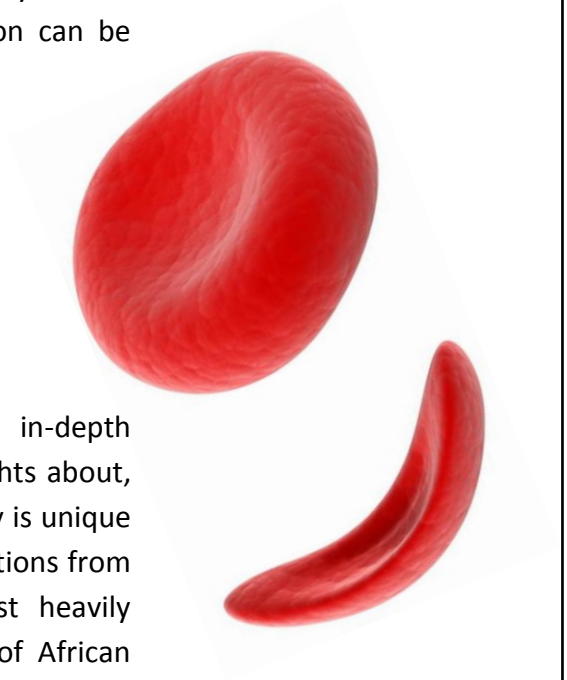
SCD is a genetically transmitted chronic blood disorder. SCD can lead to blockages among cell walls that slow or stop the flow of blood and consequently, the body's oxygen level (National Heart, Lung, and Blood Institute, 2016). SCD is an illness that affects millions of people for the entirety of their lives (National Heart, Lung, and Blood Institute, 2016; Centers for Disease Control and Prevention, 2016). The most common type of SCD is known as sickle cell anemia and is caused when children inherit two abnormal hemoglobin genes, one from each parent.

According to the Centers for Disease Control and Prevention (CDC, 2016), SCD is especially common among ethnic minorities, including descendants of sub-Saharan Africa, and Spanish-speaking countries in the Western Hemisphere (South America, the Caribbean, and Central America). This is evidenced through incidence statistics.



Despite carrying the greatest disease burden for SCD, there is limited research regarding African Americans' knowledge and thoughts about clinical trials studying the health impacts of SCD. As noted by the Food and Drug Administration (FDA, 2017), minority group members may be more vulnerable to some diseases, but, historically, they are underrepresented in clinical trials. According to the FDA's director of the Office of Minority of Health, one reason for low minority participation in clinical trials is the long-standing history of medical mistrust that has developed within the African American community (2017). An extensive body of research examines racial disparities in medical mistrust and the impact of this mistrust on health outcomes (e.g., Brandon, Isaac, & LeVeist, 2005; Corbie-Smith, Thomas, & St. George, 2002; Gamble, 1993). One study (Corbie-Smith et al., 1999) reported that African American participants identify mistrust of medical professionals, scientists, and the government as barriers to participation in clinical studies. Corbie-Smith and colleagues (1999) also report African American participants' recommendations for improving minority participation in clinical research. Thus, while there has been a long-standing history of medical mistrust, which has led to less participation in clinical research by African Americans, there is some evidence that minority participation can be increased.

An extensive body of research examines racial disparities in medical mistrust and the impact of this mistrust on health outcomes (e.g., Brandon, Isaac, and LeVeist, 2005; Corbie-Smith, Thomas, and St. George, 2002; Gamble, 1993).



Researchers in the present study sought to gain a more in-depth understanding of African Americans' knowledge of, and thoughts about, clinical trials investigating the health impacts of SCD. This study is unique in that it seeks to gain first-hand knowledge about SCD perceptions from a large sample of African Americans, the population most heavily burdened.[i] Few studies have been able to amass a sample of African Americans as large as this study. Thus, a comprehensive understanding of this population's perceptions can be gleaned from the study's findings.

GOALS

Our primary goals are to assess:

1. General Knowledge of SCD; and,
2. Motivators for Behavioral Changes

We hypothesize that:

1. Most African Americans are unaware of the significant impact that SCD has on both the quality of life and life expectancy; and,
2. African Americans are more willing to learn about SCD and other health-related issues from physicians, trusted community leaders, friends, and family than from other sources, such as the news media.

Results from this poll will provide insight into the perceptions, understanding and views of clinical trials among the African American community. We intend to gain better insight as to why African Americans are hesitant to participate in clinical trial research due to perceived expense, inconvenience, lack of trust in the medical system, and safety concerns.

METHOD AND SAMPLING

3.1 | *Method and Research Design*

The study took a quantitative survey approach, using correlational analysis. Data were gathered by way of a questionnaire developed by the Pfizer Rare Disease Team and the National Newspaper Publishers Association (NNPA), in coordination with researchers in the Howard University Public Opinion Group. Pfizer Rare Disease provided the funds for the study with the goal of obtaining scientific data to better understand participants' awareness of the disease, their motivational mechanisms to seek information about the disease, and their perceptions of clinical trials associated with detecting and treating the disease. A correlational design was used for this study.

The national poll aimed to complete telephone interviews with a minimum of 600 individuals. A total of 741 surveys were completed, drawing from more than 20,000 telephone calls. The telephone interview

is an accepted and often used approach for quantitative data collection; it is a principal survey method (Aday, 1996), and is the most widely used survey modality (Bernard, 2002). Telephone interviews are helpful because they provide wide geographic access, decreased research and travel costs, control of interviewer-procedures, and studies have shown that respondents are more relaxed and able to disclose sensitive information (Novick, 2008). Clearly, for the purposes of this study, the telephone interview was most suitable.

3.2 | *Sample*

The poll was conducted at Howard University using a nationally representative poll of the African American population to accurately measure the knowledge, perceptions, and behavior of the community with regard to SCD. The sample was selected using a random digit survey of landline and cell phone numbers. Weighted to the African American population projected by the Census in the American Community Survey, we matched the age and gender profile of the African American population.

Our goal was to interview a large sample in order to assess and report differences by gender, income, education, occupation, region, and other characteristics. This information can assist us, and those in product development, by providing a deeper understanding of participants' concerns, information, modes of communication, understanding, feelings, and personal familiarity involving SCD.

3.3 | *Procedures*

The poll was carried out by a multidisciplinary research team of Howard University professors in the fields of sociology, communications, and political science who trained and supervised graduate and undergraduate students making the calls (See Appendix B). A polling center with 10 calling stations was created by the research team to accommodate the calling, which was conducted from 10 a.m. to 10 p.m., seven days a week for a period of one month.

The research team sought a minimum random sample of 600 respondents. Calls began with a database of over 40,000 phone numbers (both land line and cell phones) belonging to residents in zip codes with

high African American populations. Callers asked those they reached if they were African American and omitted all who answered no. At the close of the study on July 15, 2017, 31,934 calls had been made. The interview team consisted of one project manager, two software/computer technicians, four shift advisors, and 39 student interviewers, in addition to the faculty research team.

Prior to the initiation of the study, each interviewer was trained in telephone-interviewing procedures through a series of workshops and one-on-one coaching. Interviewers followed the Howard Institutional Review Board's approved script when speaking to participants.

Under the supervision of the project manager, callers used a computer-assisted, telephone-interviewing system. When the prospective participant answered the phone, the interviewers read a short statement (See Appendix A) concerning the project, queried the prospective respondent as to his/her legal age (18 years of age), and invited the respondent to take part in the poll. Interviewers posed questions provided by the survey instrument (written and pre-tested by the research team). Respondents who agreed to participate in the study were screened for eligibility.

Interviewers briefly explained the survey along with a statement affirming the confidentiality of the responses. Interviewers electronically recorded respondents' answers to questions. Informed consent was obtained from research participants (See Appendix A). The survey instrument included 31 questions (See Appendix A) regarding SCD. At the completion of the survey, participants were thanked for their time and participation in the study.

No sensitive information was gathered during the interviews. The study had minimal risks and was approved by the Howard University Institutional Review Board (IRB).

3.4 | *Data Analysis*

Using pre-programmed software, a series of correlations and multiple regressions were used to examine the relations among variables relevant to the hypotheses. The data were then assessed using other statistical

tests via Excel and the Statistical Package for the Social Sciences (SPSS) software programs.

SUMMARY OF FINDINGS

The most compelling finding in this survey is that African Americans nationally have been directly or indirectly exposed to substantial information about the disease. Overall, the majority is concerned with the prevalence of SCD and is troubled by its disproportionate impact on African Americans. In addition, many expressed the need for additional current information on the disease and treatment options. Specifically, respondents were interested in pain relief, the effectiveness of clinical trials, and any progress toward a cure or better treatment.

We interviewed 741 individuals 20–70 years of age (See Table 1). This number includes both African American males (27.5%) and females (72.4%). A majority of the sample had some college or professional training (29.2%), but there was a relatively even distribution by education. While a large portion of the sample refused to answer the questions regarding income, 15.0% indicated earning between $36,000 and $50,000 annually, and 17.7% disclosed an income between $51,000 and $80,000. The majority fell in or below this latter income group.

Table 1 describes the profile of respondents. Overall, 91.81% (*N*=741) respondents had previously heard of SCD. When asked about their knowledge of sickle cell and its origin, 78.7% responded it was acquired by genetics/inheritance, while 18.1% reported “unsure.”

Table 1- SCD Telephone Interview Sample

PROFILE OF RESPONDENTS	
Age	%
Under 20	0.8
20-30	9.3
31-40	10.4
41-50	17.1

51-60	18.4
61-70	19.6
Over 70	22.6
No Answer	1.6
Gender	**%**
Female	72.4
Male	27.5
Other	0.1
Education	**%**
No HS Diploma	2.9
HS Diploma/GED	21.1
Some College or Professional	29.2
College Degree	27.7
Master's Degree	14.3
Advanced Degree (Ph.D., JD, etc.)	4.9

Income	**%**
Under $20,000	12.7
$21,000 - $35,000	11.2
$36,000 - $50,000	15.0
$51,000 - $80,000	17.7
$81,000 - $100,000	8.7
Over $100,000	13.1

No Response	21.6

4.1 | *General Knowledge of SCD*

Participants were asked to describe their general knowledge of SCD (See Table 2), and of those who had heard of SCD, many demonstrated accurate understanding. In other words, participants understood the fundamental concepts of SCD. Close to 90% (87.6%) understood that SCD is a blood disorder, and 78.7 % understood that it is acquired through genetics/inheritance. When asked about the importance of information about SCD compared to other health conditions such as heart disease, diabetes, or kidney disease, 67.2% of the participants described SCD as "just as important" to other health conditions. There were other "significant general knowledge of SCD points of view" that the polling data revealed, including the following: 85.4% understand people with SCD experience chronic fatigue that may cause them to miss school or work; 86% know the pain caused by SCD can occur in multiple parts of the body; 81% believe when having a pain crisis, people with SCD often need to go to the ER for help; 60% state that people with SCD can easily get addicted to pain medication; and 11.8% believe SCD is "more important" than other health conditions, while 67.2% believe that information about SCD is "just as important as" other health conditions.

Table 2- General Knowledge

Question	Yes	No	Don't Know
Q.2 "Have you heard of sickle cell disease?"	91.6%	8.4%	0.0%
Q.8. "Do you think that sickle cell can lead to other health problems?"	82.2%	3.1%	14.7%
Q.12 **"…Sickle cell affects only…African descent?"**	35.7%	64.3%	0.0%

Note 1- Numbers Based on Percentages (n=820)

While 82.2% stated that SCD could lead to other health problems, 14.7% were unsure. Participants were also unaware on the longevity of the

disease. Specifically, 32.6% said they were unsure. Also, noteworthy, 64.3% reported that the disease does not only affect people of African descent.

4.2 | *Behavior/Educational Resource*

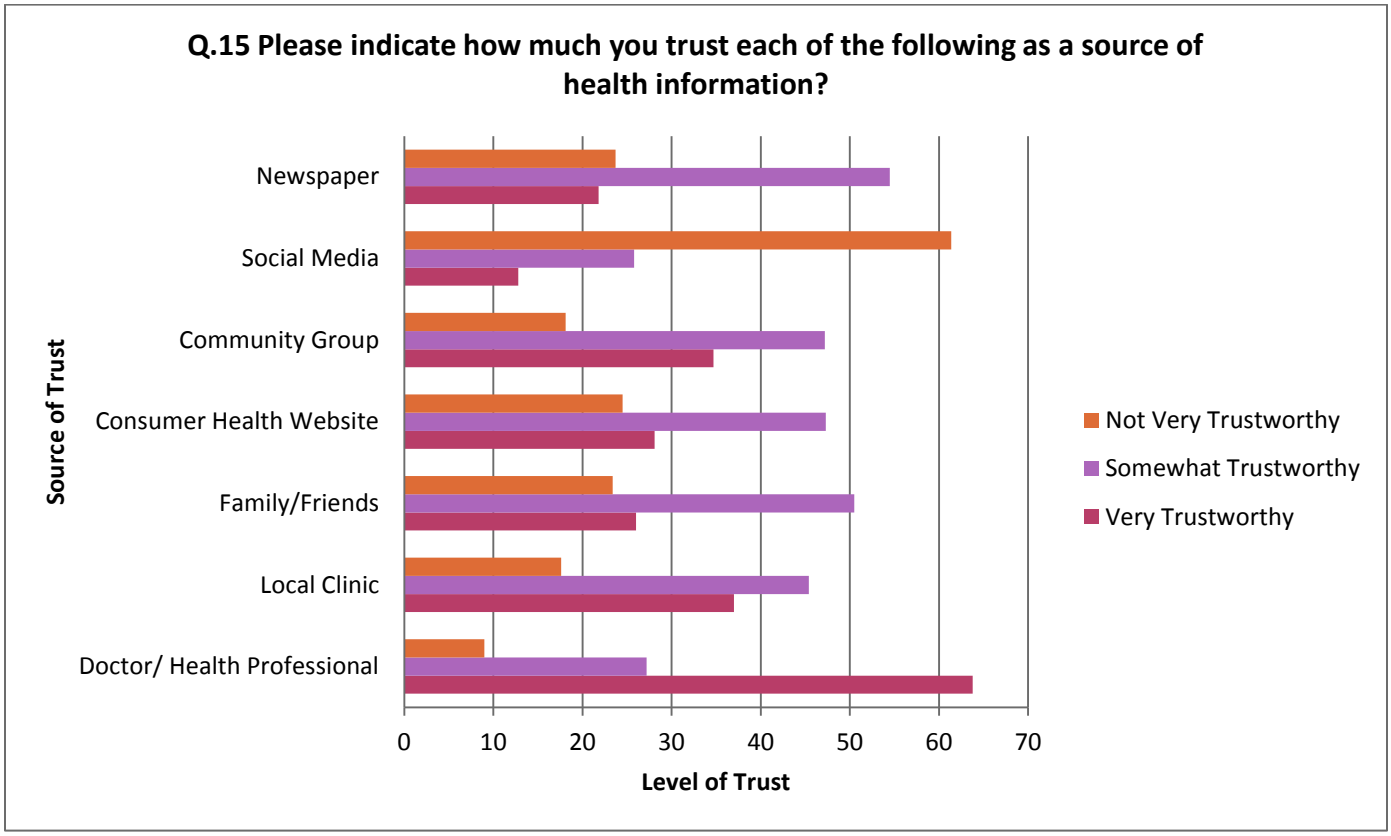
Interviewers also asked questions concerning behaviors and educational resources. When asked, "What might motivate you to learn more about a particular health condition?" the majority of participants said they were motivated to learn about SCD if they thought they might have it (49.6%). However, nearly 5% reported that they would also seek additional information out of general curiosity (5.1%).

Trust on Sources of Information

When asked about the levels of trust toward information sources (See Figure 1), African Americans expressed a great deal of trust in physicians and healthcare professionals for information on the disease, but very little trust in social media as a source of information. About 86% of respondents said physicians were *very trustworthy* (63.8%) or *somewhat trustworthy* (27.2%). In contrast, only 12.8% thought of social media as trustworthy, while 25.8% thought of social media as somewhat trustworthy.

As a source of information, newspapers fall somewhere between, but on the positive side. The clear majority, 79%, see them as a trustworthy (21.8%) or somewhat trustworthy (54.5%) source of information on the disease (See Table 4).

Figure 1- Sources of Trust



As noted above, despite previous literature, participants described feeling very trustworthy toward their healthcare providers. There were very few differences between male and female participants when it came to trust in their doctors and health care providers (See Table 3).

Table 3- Gender & Trust in Doctor

Gender x Trust in Doctor Crosstab						
						Total
			Very Trustworthy	Somewhat Trustworthy	Not Very Trustworthy	
Gender	Female	Count	342	146	44	532
		% within Gender	64.3%	27.4%	8.3%	100.0%
	Male	Count	129	57	18	204
		% within Gender	63.2%	27.9%	8.8%	100.0%
	Other	Count	1	0	0	1
		% within Gender	100.0%	0.0%	0.0%	100.0%
Total		Count	472	203	62	737
		% within Gender	64.0%	27.5%	8.4%	100.0%

Overall, respondents reported low levels of trust for various sources of information, including local clinic, family and friends, consumer health websites, social media, and newspapers (20-23%). Specifically, in regard to physicians and health care providers, 63.8% reported being “very trustworthy,” although they did not demonstrate full confidence.

Table 4- Source of Trust

Source	Very Trustworthy	Somewhat Trustworthy	Not Very Trustworthy
Doctor/Health Professional	63.8%	27.2%	9.0%
Local Clinic	37.0%	45.4%	17.6%
Family/Friends	26.0%	50.5%	23.4%
Consumer Health Website	28.1%	47.3%	24.5%
Community Group	34.7%	47.2%	18.1%
Social Media	12.8%	25.8%	61.4%
Newspaper	21.8%	54.5%	23.7%

4.3 |*Perceptions, Understanding, and Views of Clinical Trials*

Participants were asked to describe their perceptions, understanding, and views of clinical trials. When asked about experience with being invited to participate in a clinical trial, of those who responded just over half (56.0%) reported "yes" and 44.0% reported "not having been recommended."

When asked, "How much interaction have you had with clinical research personnel or agencies," 31.8% of the sample reported "No interaction," 22.2% reported "Some interaction," and 12.9% reported "A lot of interaction." Approximately a quarter of the sample (28.2%) reported a willingness to participate in a clinical trial if it was recommended by their doctor, while 30.8% reported that they would not. In addition, the polling data revealed the following: 80.6% of participants feel clinical trials are

necessary for developing new medications to treat diseases; and, 70.6% believe without enough people to participate in a clinical trial, a new drug may not be able to get developed.

Attitudes Toward Clinical Trials

Participants were asked about their attitudes concerning clinical trials on a Likert-scale item with responses ranging from *very negative to very positive*. Most participants reported *very negative (45.8%*) or *somewhat negative attitudes* (36.5%), while others reported a *neutral attitude* (17.7%) (See Table 5).

Table 5- Attitude Toward Clinical Trials

		Valid Percent
What is your attitude toward clinical trials?	Very Negative	45.8
	Somewhat Negative	36.5
	Neutral/Balanced	17.7
	Somewhat Positive	0
	Very Positive	0
	I Don't Know	13.1
	Total	100.0

When asked, "Why wouldn't you participate in a clinical trial?", the poll documented the following range of answers:

- 44.5% stated, "Fear of uncertainties…."
- 18.2% stated, "Mistrust…"
- 17.4% stated, "Other…."
- 8.5% stated, "Being in a trial wouldn't do much good."
- 2.8% stated, "Because of past experiences…."
- 0.9% stated, "Cost…"

In contrast, when asked, "*What is your attitude toward clinical trials in sickle cell disease?",* respondents recorded similar responses (See Table

6). 3% reported having “very negative attitudes,” 7.4% “somewhat negative attitudes,” 33.2% reported “neutral feelings,” 25.2% reported “somewhat positive attitudes,” 17.5% reported “very positive attitudes,” and 13.6% reported, “don’t know.”

Table 6- Attitude Toward Clinical Trials (SCD)

		Valid Percent
What is your attitude toward clinical trials in sickle cell disease?	Very Negative	3.1
	Somewhat Negative	7.4
	Neutral/Balanced	33.2
	Somewhat Positive	25.2
	Very Positive	17.5
	I Don’t Know	13.6
	Total	100.0

Our findings demonstrate that African Americans are open and willing to engage more fully in the effort to overcome SCD.

Age and Willingness to Participate in a Recommended Clinical Trial

In regard to age, participants over 31 (the majority of these young adult and older participants), report positive attitudes toward clinical trials, and clinical trials about SCD (73.4%). Only those 30 and younger indicate an unwillingness to participate in clinical trials.

Table 7- Attitude Toward Participating in Clinical Trials (SCD)

Age * Would you be willing to participate in a (or another) clinical trial if recommended by your doctor?					
			Yes	***No***	***Total***
Age	Under 20	Count	2	4	6
		% within Age	33.3%	66.7%	100.0%

	20-30	Count	36	32	68
		% within Age	52.9%	47.1%	100.0%
	31-40	Count	53	24	77
		% within Age	68.8%	31.2%	100.0%
	41-50	Count	80	45	125
		% within Age	64.0%	36.0%	100.0%
	51-60	Count	79	55	134
		% within Age	59.0%	41.0%	100.0%
	61-70	Count	69	73	142
		% within Age	48.6%	51.4%	100.0%
	Over 70	Count	83	79	162
		% within Age	52.9%	47.1%	100.0%
	8	Count	5	5	10
		% within Age	50.0%	50.0%	100.0%
Total		Count	407	317	724
		% within Age	56.2%	43.8%	100.0%

Income and Willingness to Participate in a Recommended Clinical Trial

When asked if they would be willing to participate in a clinical trial, participants' responses did not vary significantly as a function of income. However, the data reveal that older adults (50 and over) are more likely to participate in a clinical trial.

Table 8- Income & Clinical Trial

Income * Would you be willing to participate in a (or another) clinical trial if recommended by your doctor?					
			Yes	***No***	***TOTAL***
Income	**Under 20k**	Count	38	54	192
		%	41.3%	58.7%	100.0%
	21-35k	Count	52	30	82
		%	63.4%	36.6%	100.0%
	36-50k	Count	60	50	110
		%	54.4%	45.5%	100.0%
	51-80k	Count	81	48	129
		%	62.8%	37.2%	100.0%
	81-100k	Count	42	22	64
		%	65.6%	34.4%	100.0%
	Over 100k	Count	69	26	95
		%	72.6%	27.4%	100.0%
	No Answer	Count	63	86	149
		%	42.3%	57.7%	100.0%
Total		Count	405	316	721
		%	56.2%	43.8%	100.0%

DISCUSSION

This study found that the majority of the African American community polled are aware of SCD and consider information about the disease to be important. While historical contexts and research suggest that African Americans are hesitant and unwilling to participate in clinical trials, findings from this study indicate that African Americans are willing to

participate in clinical trials with proper knowledge and recommendations from trusted healthcare providers. While attitudes toward clinical trials were found to be similar to previous literature (very negative - 45.8%; somewhat negative - 36.5%), participants did describe a willingness to consider clinical trials concerning SCD. However, it is important to note that the demographics for this study's sample were skewed. Over 50% of the respondents were female and college educated. Thus, we still have gaps in our knowledge about other groups. However, when seeking to understand the roles of gender, age, income, and education in individuals' willingness to participate in clinical trials, the data suggest minimal social demographic differences and reasonably high levels of trust in the medical system, as well as openness to participating in clinical trials. This also suggests that African Americans, despite certain constraints, would consider participating in studies that would benefit the health outcomes associated with SCD.

CONCLUSION

Overall, this study has shown that African Americans are directly or indirectly familiar with SCD. With sufficient knowledge provided to them, African Americans are more inclined to consider participation in a medical research study to assist in finding better treatments for SCD.

ACKNOWLEDGEMENTS

The authors would like to thank the research team for their advice and many helpful suggestions while developing and editing the report (See Appendix B for complete list of personnel). We would also like to thank the Cathy Hughes School of Communications for hosting the calling center for interviewers to conduct the calls.

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APPENDIX A

Questionnaire

Howard University Sickle Cell Poll

Preamble: Hello, is this [STUDENT'S NAME]? I'm a student at Howard University, working with Dr. Adams in Sociology and Dr. Byerly in the Department of Communication and Cultural Studies. Our study has been approved through the university's official internal review process.

We are talking to African Americans about their awareness of sickle cell disease. May I verify that you are African American? [IF YES, PROCEED. IF NOT, THANK THE PERSON AND END.]

Participants must also be over the age of 18 -- may I ask if you are 18 or older? [IF ANSWER IS NO, THANK THEM AND HANG UP. IF YES, PROCEED]

Do you have 5-10 minutes to answer a few questions? [IF ANSWER IS YES, PROCEED].

Your participation in this poll will help us better understand African Americans' awareness of SCD. Everything you share with me will be confidential – in other words, your identity will never be revealed in any way. The entire poll will take approximately 10 minutes to complete, and your participation is completely voluntary. You can choose not to answer questions that make you uncomfortable, and you can discontinue your participation at any time. You may also end the survey anytime you wish. Your legal rights will not be violated by your participation in this survey.

Are you willing to participate in the survey?

Should you have any questions about the survey or your participation in it, you may reach Dr. Adams or Dr. Byerly at (202) 806-6700, (202) 806-5121, or contact the Howard University Institutional Review Board at (202) 865-8597.

Questions

General Knowledge of SCD Questions

1. Have you heard of sickle cell disease?
    - Yes
    - No (Skip to Question 15)

2. How do you know about sickle cell disease? (indicate all that apply)
    - My doctor/healthcare professional
    - Friend/family member has it
    - I have sickle cell disease/carry the sickle cell trait (If selected, skip to Question 5)
    - News article or segment
    - Other source

3. Have you been tested for sickle cell disease?
    - Yes (please indicate)
        - At birth
        - As a child
        - As an adult
        - No
        - I don't know/I'm not sure

4. How important is information about sickle cell disease to you, compared to other health conditions such as heart disease, diabetes, or kidney disease?
    - More important
    - Just as important
    - Not as important

5. To the best of your knowledge, what is sickle cell disease? (select one answer)
    - A blood disorder
    - An infectious disease
    - A bone disease
    - An eye disease
    - I don't know/I'm not sure

6. Do you know how someone gets sickle cell disease? (select one answer)
    - Sickle cell disease is contagious, like a cold or flu
    - It is genetic, you inherit it from your parents
    - I can get it from a bad blood transfusion
    - Sickle cell disease is sexually transmitted
    - I don't know/I'm not sure

7. How is sickle cell disease diagnosed? (select one answer)
    - Newborn screening/blood test
    - As part of a regular physician check-up
    - As part of HIV screening
    - As part of STD screening
    - I don't know/I'm not sure

8. Do you think that sickle cell disease can lead to other health problems?
    - Yes
    - No (Skip to Question 11)
    - I don't know/I'm not sure (Skip to Question 11)

9. Which of the following health problems do you think can be caused by sickle cell disease? (indicate all that apply)
    - Stroke

- Chronic Pain
- Organ Damage
- Fatigue
- Acute Chest Syndrome
- None of the above

10. Do you know if there are any treatments available for sickle cell disease?
    - Yes, there are treatments that cure sickle cell disease
    - Yes, there are treatments for the symptoms, but no cure
    - No, there are no treatments
    - I don't know/I'm not sure

11. How long do people in the US with sickle cell disease live?
    - 20-40 years
    - 40-60 years
    - 60+ years
    - Not sure

12. Do you agree with the following statement? Sickle cell disease affects only people of African descent. (choose one)
    - Yes
    - No

13. On a scale of 1-5 (where 1 is "do not agree" and 5 is "completely agree"), please indicate your level of agreement with the following statements.
    - People with sickle cell disease experience chronic fatigue that may cause them to miss school or work
    - The pain caused by sickle cell disease can occur in multiple parts of the body
    - When having a pain crisis, people with sickle cell disease often need to go to the emergency room for help
    - People with sickle cell disease can easily get addicted to pain medication

<u>Behavior/Educational Resource Questions</u>

14. What might motivate you to learn more about a particular health condition? (indicate all that apply)
    - If I think I might have it
    - If I am diagnosed with it
    - If a family member/friend has it/may have it
    - Stories I hear from friends or family about other people who have it
    - Stories I see in the media or online about people who have it
    - If the disease affects mostly African Americans
    - General curiosity
    - Other, please specify

- None of the above

15. Please indicate how much you trust each of the following as a source of health information? The options are "Very Trustworthy," "Somewhat Trustworthy," "Not Very Trustworthy."
    - Doctor/healthcare professional
    - Local clinic
    - Family/friends
    - Consumer Health Website like WebMD (if possible, ask which one for open-ended response)
    - Community group or health advocacy organization
    - Social media (Facebook, Twitter, etc.)
    - Newspaper, magazine or TV news
    - Other

16. With whom are you most likely to discuss a personal health concern?
    - Spouse/Partner
    - Parent
    - Child(ren)
    - Other family member (if possible, determine which family member for open-ended response)
    - Friends
    - Doctors/HCPs
    - Leaders/members of community group/health advocacy organization
    - Other

<u>Perception, Understanding/Views of Clinical Trials</u>

17. How much interaction have you had with medical research?

18. Have you ever heard the term "clinical trial" or participated in a clinical trial?
    - Yes, I've heard the term
    - Yes, I've participated in a clinical trial
    - No (Skip to Question 21)

If respondent answers "no" to having heard of clinical trials (Question 18), skip to Question 21 and provide brief description. "Clinical trials are used to evaluate the safety and effectiveness of potential new medications by monitoring their effects in patients who volunteer to participate."

19. Has anyone ever recommended that you participate in a clinical trial?
    - Yes
    - No

20. Have you ever heard or received information about clinical trials from any of the following sources? (indicate all that apply)

- Physician/healthcare professional
- Newspaper/radio advertisement
- Community group or healthcare advocacy organization
- Internet/social media
- Family member/friend
- News story
- Other

Based on your knowledge and experience of clinical trials:

21. What is your attitude toward clinical trials? (choose one)
    - Very negative
    - Somewhat negative
    - Neutral/balanced
    - Somewhat positive
    - Very positive
    - I don't know

22. What is your attitude toward clinical trials in sickle cell disease? (choose one)
    - Very negative
    - Somewhat negative
    - Neutral/balanced
    - Somewhat positive
    - Very positive
    - I don't know

23. What would you say influences your views of clinical trials?

24. Please rate on a scale of 1 to 5 (where 1 is "do not agree" and 5 is "completely agree") your level of agreement with the following statements:
    - Clinical trials are necessary for developing new medications to treat diseases.
    - Without enough people to participate in a clinical trial, a new drug may not be able to get developed.
    - People who participate in clinical trials are treated like guinea pigs.

25. Would you be willing to participate in a (or another) clinical trial if recommended by your doctor?
    - Yes (End poll)
    - No (Go to Question 26)

26. Why wouldn't you participate in a clinical trial if recommended by your doctor? (indicate all that apply)
    - Being in a trial wouldn't do much good
    - Fear of uncertainties related to the trial and being on a new, unknown treatment
    - Mistrust of the medical system

- Because of past experiences by other African Americans
- Cost and logistical issues
- Other

Demographic Questions

27. How would you characterize your gender?
    - Female
    - Male
    - Other

28. What is the highest level of education completed?
    - No high school diploma
    - H.S. diploma/GED
    - Some college or professional school
    - College degree
    - Master's degree
    - Advanced graduate degree (Ph.D., J.D.)

29. May I ask about your age? Are you:
    - Under 20
    - 20-30
    - 31-40
    - 41-50
    - 51-60
    - 61-70
    - Over 70__?

30. What is your current employment status? (student, full-time employment, part-time employment, unemployed)

31. Would you describe your household income as:
    - Under 20K
    - 21-35K
    - 36-50k
    - 51-80K
    - 81-100k
    - Over 100K

THANK YOU FOR YOUR PARTICIPATION IN THIS SURVEY.

NOTE: There may be some useful correlations on the news sources and information levels.

[i] Searches of the literature on communications and/or awareness of sickle disease produced little directly relevant research. Out of more than 150 articles sampled on awareness and communications none developed survey data on access to medication and clinical trials. Still, some useful information is available. For example, a 2006 study published in the *Journal of the National Medical Association* used three focus groups of "healthcare providers, people affected" by SCD and trait, and "community members." Notably, the authors recommend: "A baseline of community perceptions, knowledge, and attitudes about SCD and SCT needs to be established to provide a foundation for effective intervention" [Treadwell, 2006: 708].

Another study published in the same journal surveyed 162 African American women, and out of 264 contacted through "a cross-sectional telephone survey," found that there was "inadequate" information about the disease [Boyd, 2007: 62].

APPENDIX B

HOWARD UNIVERSITY NATIONAL SICKLE CELL POLLING CENTER PROJECT

PROJECT TEAM ROSTER

Summer 2017

Title	Team Members	
Project Manager	Ashla Hill Roseboro	
Shift Supervisors	Jesse Card	
	Camille Dantzler	
	Keadrick Peters	
	Shannell Thomas	
	Tesfaye Abebe	Kenya Johnson
Researchers		
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	Nancy Ajaa	Ashley Lewis
	Ayana Albertini-Fleurant	Anthony Macklin
	Loy Azalia	Terry Marsh
	Gabrielle Benson	Alexis McDonald
	Noelita Bowman	Teneisha McIntyre
	Aamira Chaney	Dakota Miles
	Donshaya Courts	Brandi Montgomery
	Juone Darko-Kadiri	Pierre Ndoye
	Babatunde Falohun	Precious Ndukwe
	Augusta Fraser	Ngozi Okolo
	Angeleesha Frierson	Oluwasade Oresegun
	Cindia Fouda	Abieyuwa Salami
	Maia Fuller	Jeva St.Fort
	Danielle Gantt	Halle Stanley
	Kari Golden	Shirin Sultana
	Ashley Guthrie	Jorden Teamer
	Jason Harris	JaMaal Thompson
	Cassandra Jean	
Computer and Software Technicians	Glenn Griffin	Clinton Walker