NATIONAL
BLACK
CHURCH
INITIATIVE

www.naltblackchurch.com

The National Black Church Initiative (NBCI) Clinical Lecture Tour
2020-2022

NBCI Mission Statement

The NBCI is a coalition of 34,000 African American and Latino churches working to eradicate racial disparities in healthcare, technology, education, housing, and the environment. NBCI's mission is to provide critical wellness information to all of its members, congregants, churches and the public.

Our methodology is utilizing faith and sound health science. NBCI purpose is to partner with major organizations and officials whose main mission is to reduce racial disparities in the variety of areas cited above. NBCI offers faith-based, out-of-the-box and cutting-edge solutions to stubborn economic and social issues. NBCI's programs are governed by credible statistical analysis, science-based strategies and techniques, and methods that work.

Purpose

The purpose of the lecture tour over the next 15 months is to showcase the top 15 African Americans clinicians in the country in their various clinical fields of expertise. This tour will include lectures on the importance of African American participation in clinical trials, and the role of the Black Church using its Clinical Trials Education Awareness and Participation Program (CTEAPP) clinical trial model.

Purpose cont.

Number two, it's to demonstrate the CTEAPP methodology and the promises it offers in impacting and increasing the participation of African Americans in clinical trials (link), transforming the approach of the pharmaceutical industry and how they work with African American clinicians & the general public, and implementing CTEAPP as its model.

Purpose. cont

The third thing is that the lecture tour will serve as a data collection platform to identify key stakeholders in the African American community (including, lawyers, doctors, pharmacists and all health personnel), as well as computerize about 300,000 to 400,000 on individuals who want more information on clinical trials across the country. All of the information collected will be voluntary. The data points for these will be email address, geographic location, any contact information, Twitter, Facebook, and any other self-disclosed information. This pool of information should be carefully collected by Hipper. We will utilize the list to announce ongoing and forthcoming clinical trails in all geographic areas applying NBCI facecommand structure, zip codes, cities, and other identifiable factors to make sure that we can match the individuals who wanted more information concerning participation with our partners and clinical trials being conducted.

Who is NBCI?

The National Black Church Initiative (NBCI) is a coalition of 34,000 African-American and Latino churches working to eradicate racial disparities in healthcare, technology, education, housing, and the environment. NBCI's mission is to provide critical wellness information to all of its members, congregants, churches and the public. The National Black Church Initiative's methodology is utilizing faith and sound health science.

The aim is to offer our member congregants and the public helpful and healthy science-based tips on how to develop and maintain a healthy lifestyle. The website also offers the latest information on housing, education, technology and environmental issues.

The National Black Church Initiative's purpose is to partner with major organizations and officials whose main mission is to reduce racial disparities in the variety of areas cited above. NBCI offers faith-based, out-of-the-box and cutting-edge solutions to stubborn economic and social issues. NBCI's programs are governed by credible statistical analysis, science-based strategies and techniques, and methods that w

What is the NBCI Health Emergency Declaration?

The National Black Church Initiative declared a national health emergency in the Black Church highlighting the health crisis in the African American community. This paper explains why we are taking such dramatic actions and the proven, scientific methods we will be using to solve the crisis.
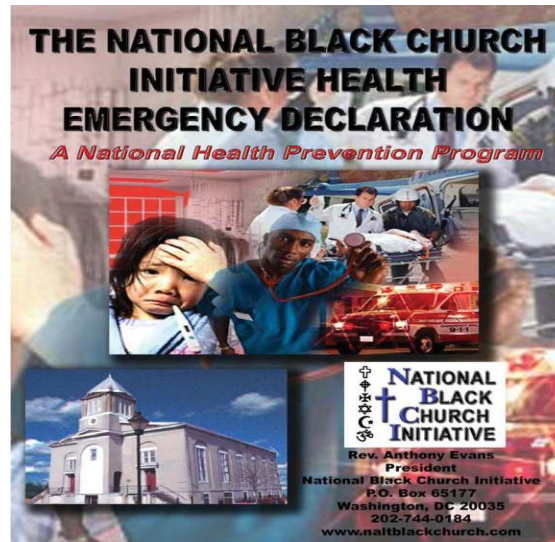
Appendix 1

How is NBCI Organized?
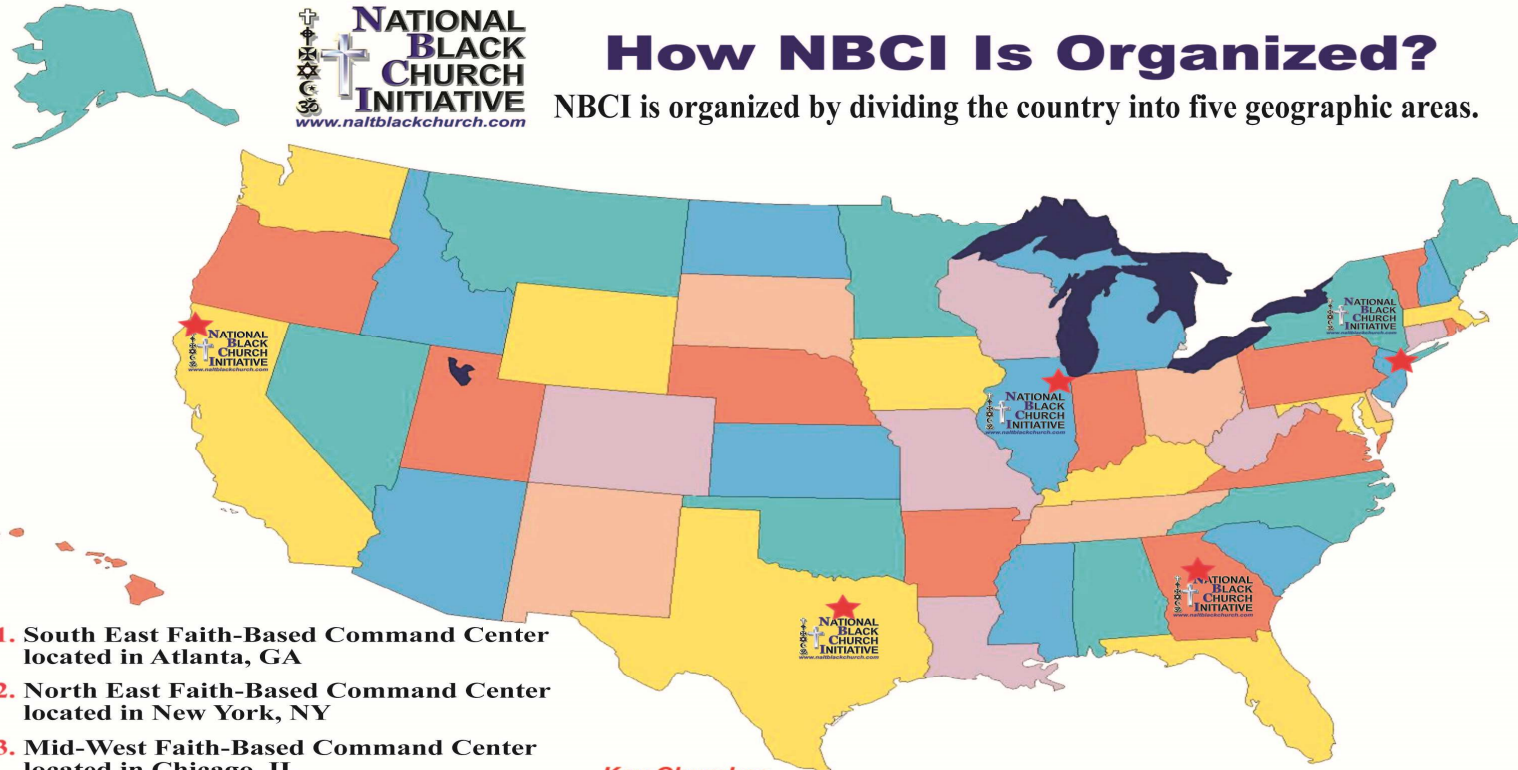
How NBCI Is Organized?

NBCI is organized by dividing the country into five geographic areas.

1. **South East Faith-Based Command Center** located in Atlanta, GA
2. **North East Faith-Based Command Center** located in New York, NY
3. **Mid-West Faith-Based Command Center** located in Chicago, IL
4. **Western Faith-Based Command Center** located in Oakland, CA
5. **South West Faith-Based Command Center** located in Dallas, TX

Key Churches
- We divide every metropolitan city and rural area into key churches. These churches are placed strategically to cover all geographic areas.
- The number of key churches that we designate for any given area depends upon the size of the population of the state or the city.

NBCI Churches Zip Codes **Appendix 2**

Breakdown of NBCI Churches by States **Appendix 3**

What Is NBCI COMMUNICATION AND DISTRIBUTION NETWORK?

We will activate both NBCI's Communication and Distribution Network and NBCI Technology Distribution Network.

NBCI has 34,000 African American churches and 116,000 sister churches. Because of our enormous size, we are able to conduct targeted distribution of health literature and other materials. This makes us one of the largest distribution networks in the country. We can quickly increase our distribution network to all NBCI churches, and our sister churches (116,000 Black churches who are not members of NBCI but is a part of our overall Black Church network), or other churches outside our distribution network.

With this enormous distribution network, we can touch every metropolitan and rural area in the country where African Americans and Latinos reside. We also can create literature both in Spanish and in English. Having this reach gives us a unique service to reach into metropolitan areas and deliver literature to zip codes, wards of cities (city election boundaries), as well as to specific neighborhoods. Over the years, we have been able to perfect this particular distribution network.

This is one of NBCI's strong suits, and we are developing new technologies and strategies to improve the accuracy and speed of delivery of critical health information and other materials that will strategically affect the African American and Latino communities.

Appendix 4

Who are our Scientific Partners?

Bridge Clinical
www.bridgeclinical.com
We focus on five thereapeutic areas:
Oncology, Immunology, Anti-infectives, Cardiovascular, and
Endocrinology.Our work is a scientific protocol development, drug logistics,
data collection, and patient recruitment."

RokketMed
www.RokketMed.com
Making certain that every American wakes knowing they have access to
basic healthcare in their community. Making basic healthcare simple to find.
Making basic healthcare affordable to purchase. In other words, making
what many believe impossible…. Possible!

Westat
www.westat.com
We see the world through data
Westat began as a visionary startup in 1963. Now, 50+ years later with 1,900
employees, we continue to pioneer new ways to support the changing needs
of clients. Our unique collaborative culture enables us to create dynamic
multifaceted teams with broad experience across wide range of topics.

Elligo Health Research
www.elligohealthresearch.com
We bring clinical research direct to clinical health care.
At Elligo, we are redefining conventional patient recruitment to bridge the
gap between clinical research and clinical health care. Our *Goes
Direct*® approach helps solve patient access challenges by enabling clinical
research as a care option in physician practices that do not currently have the
infrastructure to conduct trials.

The National Black Church Initiative Clinical Trials Education Awareness and Participation Program (CTEAPP) Southern Strategy

CLINICAL TRIALS EDUCATION AWARENESS AND PARTICIPATION PROGRAM (CTEAPP)

Appendix 5

Who are some of the Clinicians giving the lectures

- Criteria

- We will be selecting clinicians who have made an enormous impact into particular clinical areas, who's research will effect African Americans

- These clinicians must be connected to a major teaching university, be published, and have a strong pharmaceutical relationship, committed to increasing AA in the clinical trial space

The Importance of NBCI Lecture 15 cities on Clinical Tails

NBCI/CTEAPP Lecture Series

The National Black Church Initiative is initiating a ten-part nationwide lecture series that will highlight noted African American clinicians and to further NBCI Clinical Trials Education Awareness and Participation Program (CTEAPP). The lecture series is another important building block of creating an expansive clinical trials initiative to increase minority participation. The goal of NBCI/ CETEAPP is to assure 15 percent or more black participation in clinical trials.

There are three goals of the lecture series

1. Highlight the extraordinary partnership forged between Bridge Clinical and the National Black Church Initiative --- combining science and faith.

2. Identify expert African American Clinicians who can serve as primary investigators in major clinical trial programs.

3. Build a list of 100,000 key African American stakeholders who are supportive of African American participation in clinical trials along with NBCI/HED Volunteer Health Corp.

We hope to galvanize and identify 2,500 key community stakeholders in each city of NBCI Churches who are in the health space and understand the historic importance of this movement by NBCI Clinical Trials Education Awareness Participation Program. We plan to turn these individuals into clinical trial advocates. We will provide them with the training, education, and information they need. They will our frontline advocates when we need to identify potential participants in a particular clinical trial. We plan to provide online training through a new website called www.blackchurchand clinicaltrials.com. This online educational portal for African American church members and their families will allow them to search for clinical trials of their choosing.

1. **Lupus/Black Women's Health**
2. **Rare Diseases/Infectious Diseases (HIV)**
3. **Diabetes**
4. **Eye Care and Blindness**
5. **Oncology/Cancer**
6. **Heart Disease**
7. **Hypertension**
8. **Multiple Myeloma/Blood Diseases**
9. **Nutrition and Obesity**
10. **Autism**

Appendix 7

- Lupus, Breast Cancer, Childbirth and overall Black Women's Health
- Infectious Diseases
- Rare Diseases
- Diabetes
- Eye Care & Blindness
- Cancer
- Heart Disease
- Hypertension
- Multiple Myeloma/Blood Diseases and Sickle Cell Anemia
- Nutrition and Obesity
- Autism

Graphic: How NBCI is organizes

Graphic: Population and Race

Population and Race

US States by Race

State ▲	Total	White	Black	Native	Asian	Islander	Other	Multiple	≡
Alabama	4,850,771	3,317,702	1,287,167	25,098	62,815	2,213	66,942	88,834	
Alaska	738,565	481,971	23,702	104,995	45,604	9,075	10,505	62,713	
Arizona	6,809,946	5,277,661	292,831	300,182	213,417	13,364	474,583	237,908	
Arkansas	2,977,944	2,302,141	459,969	19,476	42,368	7,062	75,106	71,822	
California	38,982,847	23,607,242	2,263,222	292,018	5,503,672	152,027	5,329,952	1,834,714	
Colorado	5,436,519	4,576,201	221,155	51,406	164,771	8,580	225,497	188,909	
Connecticut	3,594,478	2,757,064	376,240	9,385	156,450	931	183,754	110,654	
Delaware	943,732	652,170	206,290	3,482	36,553	465	18,512	26,260	
District of Columbia	672,391	273,471	321,062	1,757	25,558	289	30,961	19,293	
Florida	20,278,447	15,343,997	3,270,863	56,730	543,394	12,342	536,298	514,823	
Georgia	10,201,635	6,061,821	3,195,268	30,552	388,946	5,237	282,570	237,241	
Hawaii	1,421,658	357,308	25,884	2,756	540,556	142,600	14,056	338,498	
Idaho	1,657,375	1,507,880	11,231	21,323	22,720	2,343	47,964	43,914	
Illinois	12,854,526	9,236,701	1,833,501	29,696	671,811	4,275	767,145	311,397	
Indiana	6,614,418	5,546,787	613,060	15,027	137,680	2,635	145,791	153,438	
Iowa	3,118,102	2,824,197	106,762	10,791	71,178	2,913	39,527	62,734	
Kansas	2,903,820	2,465,518	168,470	23,503	80,738	1,923	65,253	98,415	
Kentucky	4,424,376	3,862,600	353,088	9,324	59,593	2,271	41,197	96,303	
Louisiana	4,663,461	2,909,599	1,500,648	27,094	80,980	1,401	56,216	87,523	
Maine	1,330,158	1,258,918	16,906	8,212	14,804	249	2,967	28,102	
Maryland	5,996,079	3,395,212	1,782,256	16,281	373,065	2,830	236,834	189,601	
Massachusetts	6,789,319	5,358,373	499,774	14,336	426,225	2,253	278,835	209,523	
Michigan	9,925,568	7,813,199	1,374,515	51,804	289,082	2,808	115,258	278,902	
Minnesota	5,490,726	4,598,252	326,953	57,566	255,935	1,976	95,600	154,444	
Mississippi	2,986,220	1,755,471	1,122,576	13,258	28,859	597	27,530	37,929	
Missouri	6,075,300	5,004,537	703,061	25,933	112,959	6,336	71,084	151,390	
Montana	1,029,862	916,664	4,438	66,865	7,448	571	5,492	28,384	
Nebraska	1,893,921	1,663,612	89,718	16,012	42,208	1,524	35,276	45,571	

State ▲	Total	White	Black	Native	Asian	Islander	Other	Multiple	≡
Nevada	2,887,725	1,936,453	253,013	32,426	232,502	19,019	279,977	134,335	
New Hampshire	1,331,848	1,244,260	18,632	2,148	33,313	289	7,016	26,190	
New Jersey	8,960,161	6,085,474	1,207,356	18,006	844,105	3,013	573,146	229,061	
New Mexico	2,084,828	1,547,843	42,187	197,191	29,991	1,390	197,944	68,282	
New York	19,798,228	12,638,791	3,100,685	77,130	1,652,846	7,937	1,730,813	590,026	
North Carolina	10,052,564	6,937,466	2,159,427	117,998	269,164	6,393	310,920	251,196	
North Dakota	745,475	654,024	17,365	39,507	10,197	341	6,600	17,441	
Ohio	11,609,756	9,503,779	1,428,230	21,872	235,878	3,499	103,726	312,772	
Oklahoma	3,896,251	2,828,569	283,821	289,871	80,670	5,543	105,686	302,091	
Oregon	4,025,127	3,416,776	76,347	45,332	166,351	15,157	121,000	184,164	
Pennsylvania	12,790,505	10,378,174	1,417,611	24,995	417,525	3,665	251,215	297,320	
Rhode Island	1,056,138	854,801	68,346	5,413	35,556	759	59,967	31,296	
South Carolina	4,893,444	3,292,598	1,332,110	14,992	71,994	3,015	74,328	104,407	
South Dakota	855,444	724,430	14,698	74,062	11,693	381	6,687	23,493	
Tennessee	6,597,381	5,131,786	1,107,392	17,568	110,605	3,784	88,745	137,501	
Texas	27,419,612	20,459,525	3,286,950	130,360	1,236,852	23,531	1,580,393	702,001	
Utah	2,993,941	2,600,077	33,619	32,079	67,545	26,742	150,596	83,283	
Vermont	624,636	590,499	7,921	2,072	9,680	206	2,197	12,061	
Virginia	8,365,952	5,720,209	1,605,447	22,499	520,119	5,469	200,265	291,944	
Washington	7,169,967	5,500,837	261,743	94,754	578,822	46,071	293,007	394,733	
West Virginia	1,836,843	1,714,591	65,300	3,322	14,096	541	7,193	31,800	
Wisconsin	5,763,217	4,950,577	365,884	50,094	152,325	1,811	111,435	131,091	
Wyoming	583,200	532,394	6,121	13,549	5,102	470	10,247	15,317	

Areas of data collection

NBCI Global Health Fund
NBCI Southern Clinical Strategy

NBCI Global Health Fund

Global Health Fund

Primary Objectives for this Global Health Fund in the Black Church

- The chief goal is to advocate for sound health policies for African Americans.
- The mission is to educate our congregants on the importance of a healthy lifestyle.
- The Fund will be used to advocate sound health policies by working with other Black Health Organizations.
- Our priority is to financially assist our members in the area of medication, rehabilitation, housing, food and other related health matters.

NBCI Southern Clinical Strategy:
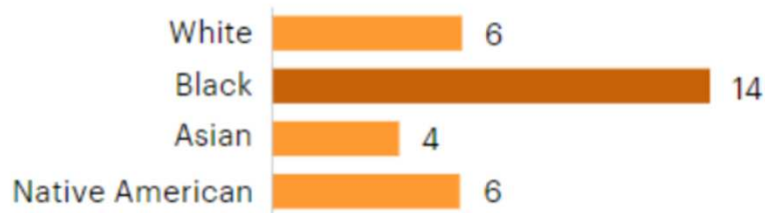# Trust Experience Access Reach Success

THE WHY

Racial Disparities in Clinical Trials
Black Patients Miss Out On Promising Cancer Drugs

- A ProPublica analysis found that black people and Native Americans are under-represented in clinical trials of new drugs, even when the treatment is aimed at a type of cancer that disproportionately affects them

- One out of five people diagnosed with multiple myeloma in the U.S. is black, and African Americans are more than twice as likely as white Americans to be diagnosed with the blood cancer

- Out of the 722 participants in the Nilarno trial, only 13 — or 1.8 percent — were black

- A ProPublica analysis of data recently made public by the FDA found that in trials for 24 of the 31 cancer drugs approved since 2015, fewer than 5 percent of the patients were black. African-Americans make up 13.4 percent of the U.S. population.

Black Americans Face the Highest Risk of Multiple Myeloma but Are Underrepresented in Trials Treating the Cancer
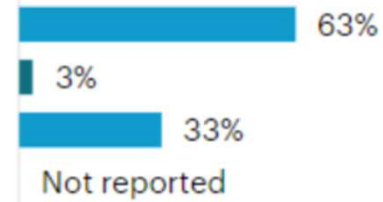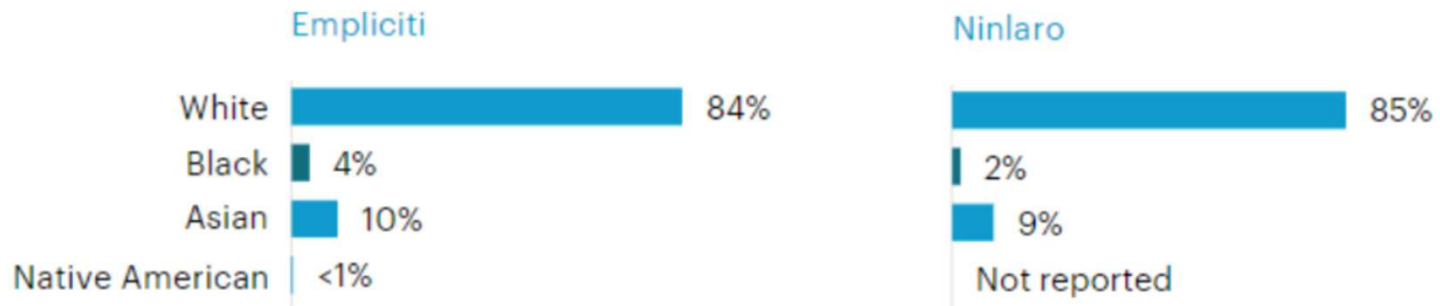
New Cases of Multiple Myeloma, Per 100,000 People

White	6
Black	14
Asian	4
Native American	6

Representation in Clinical Trials

Darzalex

White	76%
Black	10%
Asian	6%
Native American	Not reported

Farydak

White	63%
Black	3%
	33%
	Not reported

Empliciti

White	84%
Black	4%
Asian	10%
Native American	<1%

Ninlaro

	85%
	2%
	9%
	Not reported

Notes: Race was not reported for 8 percent of Darzalex's clinical trial participants, and 4.7 percent of Ninlaro's clinical trial participants.

For consistency across data sources, percentages have been rounded to the nearest integer, so numbers may not add up to 100. For some drugs, a percentage of clinical trial participants is unreported. New cases are calculated per 100,000 people by race and per year. Native American figures include both American Indians and Alaska Natives.

Southern Clinical Strategy Solution

Trust

- An initial and vital important step regarding recruitment of African Americans is the establishment of trust and credibility

- Mistrust of medical research is an extremely important barrier hindering recruitment in African American (AA) communities

- Mistrust concerns regarding previous researchers

Southern Clinical Strategy

Experience

NBCI and its SCS has enrolled thousands of patients for studies, programs and projects. We have developed a highly successful congregate recruitment formula since we began offering these services

Enrollment

Patient referrals are necessary to initiate the recruitment but, it it is patient enrollment that equates to success

Typical /traditional method
- volume referrals

NBCI SCS
- highly qualified referrals
  - more likely to be converted into randomized patients resulting in increased enrollment at participating sites

Southern Clinical Strategy

Access: rapid launch

Our SCS "trust factor" and expertise facilitates our ability to rapidly initiate recruitment of the desired patient population
- Direct patient access
- Survey data

Improved ROI

NBCI SCS

- Efficient and effective patient recruitment
- More economical and strategic approach
- Maximizing your company's investment
- The earlier the engagement of the SCS, the better your ROI

Overview of Data Collection Techniques

Technique	Key Facts	Example
Interviews	• Interviews can be conducted in person or over the telephone • Interviews can be done formally (structured), semi-structured, or informally • Questions should be focused, clear, and encourage open-ended responses • Interviews are mainly qualitative in nature	One-on-one conversation with parent of at-risk youth who can help you understand the issue Click here to see a sample key informant interview.
Questionnaires and Surveys	• Responses can be analyzed with quantitative methods by assigning numerical values to Likert-type scales • Results are generally easier (than qualitative techniques) to analyze • Pretest/Posttest can be compared and analyzed	Results of a satisfaction survey or opinion survey Click here to see an example of a survey created using the CYFERnetSEARCH Interactive Survey Builder feature. Click here to see a sample survey on middle school youth risk behavior.

NATIONAL BLACK CHURCH INITIATIVE
www.naltblackchurch.com

Clinical *Trials*

Overview of Data Collection Techniques

Observations	• Allows for the study of the dynamics of a situation, frequency counts of target behaviors, or other behaviors as indicated by needs of the evaluation • Good source for providing additional information about a particular group, can use video to provide documentation • Can produce qualitative (e.g., narrative data) and quantitative data (e.g., frequency counts, mean length of interactions, and instructional time)	Site visits to an after-school program to document the interaction between youth and staff within the program
Focus Groups	• A facilitated group interview with individuals that have something in common • Gathers information about combined perspectives and opinions • Responses are often coded into categories and analyzed thematically	A group of parents of teenagers in an after-school program are invited to informally discuss programs that might benefit and help their children succeed

Overview of Data Collection Techniques

Ethnographies, Oral History, and Case Studies	- Involves studying a single phenomenon - Examines people in their natural settings - Uses a combination of techniques such as observation, interviews, and surveys - Ethnography is a more holistic approach to evaluation - Researcher can become a confounding variable	Shadowing a family while recording extensive field notes to study the experience and issues associated with youth who have a parent or guardian that has been deployed Click here for an example of an oral history. Click here for an additional example of an oral history.
Documents and Records	- Consists of examining existing data in the form of databases, meeting minutes, reports, attendance logs, financial records, newsletters, etc. - This can be an inexpensive way to gather information but may be an incomplete data source	To understand the primary reasons students miss school, records on student absences are collected and analyzed Click here for an example of a searchable database of aggregate data on youth risk behavior.

Types of Data

Quantitative Data	- Requires use of statistical analysis - Variables can be identified and relationships measured - Counted or expressed numerically - Often perceived as a more objective method of data analysis - Typically collected with surveys or questionnaires - Often represented visually using graphs or charts

Qualitative Data	- Examines non-numerical data for patterns and meanings - Often described as being more "rich" than quantitative data - Is gathered and analyzed by an individual, it can be more subjective - Can be collected through methods such as observation techniques, focus groups, interviews, and case studies

Types of Data

Mixed Methods Data	- May increase the validity of your evaluation - May explain unexpected results obtained using only one approach (quantitative or qualitative) - Help you capture both process and outcome results - May strengthen your analysis

Social Networking Sites

Advantages	Disadvantages
• Able to reach a young demographic using a popular medium • Option to create a profile to target specific community • Ability to engage participants at remote locations in real time • Can be a rich source of quantitative and qualitative data, some of which is publicly available	• No verification of information available on public profiles • Privacy settings on profiles may impede data collection • Social networking caters to very specific demographic of users, with an average age range of 14-35 years • Consent issues involved working with underage youth (if soliciting information not publicly available on profile)

Social networking sites can include forums in which users can dialogue with one another. Data could be collected through sampling random sites for trends, soliciting information from specific users and creating a profile for data collection that attracts certain users for discussions (such as online focus groups).

Technology and Data Collection Integration

Advantages	Disadvantages
• Simpler and quicker way of collecting both quantitative and qualitative data • Easy to access a large group of respondents in geographically diverse locations • More cost effective than manually administering surveys • Data can typically be exported, eliminating manual data entry • Improves accuracy of data entry (e.g., reduces omissions, duplicate entries)	• Limited to respondents who have access to the internet • Some may find on-line interface off-putting • Does not guarantee the quality (reliability and validity) of actual survey design • Potential lack of security

Types of technology that can be used to collect data traditionally captured with surveys include:
- Online or web-based surveys
- Hand-held devices such as clickers and PDAs
- Text messages
- Social networking sites such as Twitter, MySpace, and Facebook to engage participants in a virtual focus group or conduct observations of interactions on that site