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North Carolina State Infant Mortality Collaborative

Women’s Health: Attitudes and Practices in North Carolina Focus Group Research

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Introduction

This focus group research project was undertaken as a component of the ongoing North Carolina State Infant Mortality (SIM) Collaborative. The purpose of the focus group research was to help understand the link between women's health, self-care, and infant mortality. The focus groups were conceived as exploratory in nature with the hope that they could suggest avenues for further research, whether qualitative or quantitative. The qualitative research subcommittee of the SIM Home Team served as an advisory board and resource group for this focus group research.

The focus groups were guided by a relatively new paradigm—women's overall health is the key to reducing infant mortality. According to the 2003 NC PRAMS survey more than 40 percent of pregnancies in North Carolina were unplanned. Thus, the majority of women are conceiving when they have not prepared themselves for pregnancy. Untreated health conditions or infections, close spacing of children, unhealthy behaviors, and unmanaged stress are all believed to affect the developing fetus and health of the baby. Furthermore, the vast majority of congenital birth defects occur within the first few weeks of pregnancy—before many women have any idea that they are pregnant. In this context, the best way to reduce infant mortality rates is to improve women's health.

Two overarching questions guided the research:

1. Why do women adopt (or not adopt) preventative health behaviors?
2. Why do women use (or not use) preventative health services?

These questions were operationalized in an interview guide, which was used by the focus group facilitators to guide the interviews (see Appendix B for a copy of the interview guide).

A significant limiting factor in this research was the very short timeline. (See Appendix A for an overview of the project timeline). From beginning (date of hire for the focus group coordinator) to end (production of the final report), the timeline was 77 days. We set out with the goal of recruiting and conducting 20 focus groups in this time. We were hopeful to recruit a minimum of 15 groups. Thanks to the dedication and hard work of our exceptional team of facilitators, we succeeded in conducting 21 focus groups.

Procedures

Given the extremely tight timeline for the research project (see Appendix A for a copy of the timeline), we were required to target convenience samples for the majority of focus groups. The focus group coordinator developed a list of focus group characteristics in consultation with the SIM qualitative research subcommittee. See Appendix A for a copy of the list of focus group characteristics. The rationale for the focus group characteristics was to recruit a representative sample of North Carolinians with geographic distribution across the state. Several racial or ethnic subpopulations with high or low Infant Mortality Rates (IMR) were targeted including counties with high IMR, low IMR, and “excess” infant deaths (as described by data received from the state bureau of health statistics). We intentionally attempted to recruit some focus groups that were racially, ethnically, or socio-economically homogenous in the hopes that they might be more comfortable addressing certain sensitive issues related to racial, ethnic, or economic discrimination.

Once the list of focus group characteristics was finalized, subcommittee members provided suggestions for convenience groups that fit the characteristics. In addition, some focus group facilitators used personal and professional contacts to locate or recruit certain groups. A total of 21 focus groups were recruited in 13 counties across the state. See Figure 1 for a map of the geographic distribution of the focus groups. See Appendix D for a list of the focus groups and their characteristics.

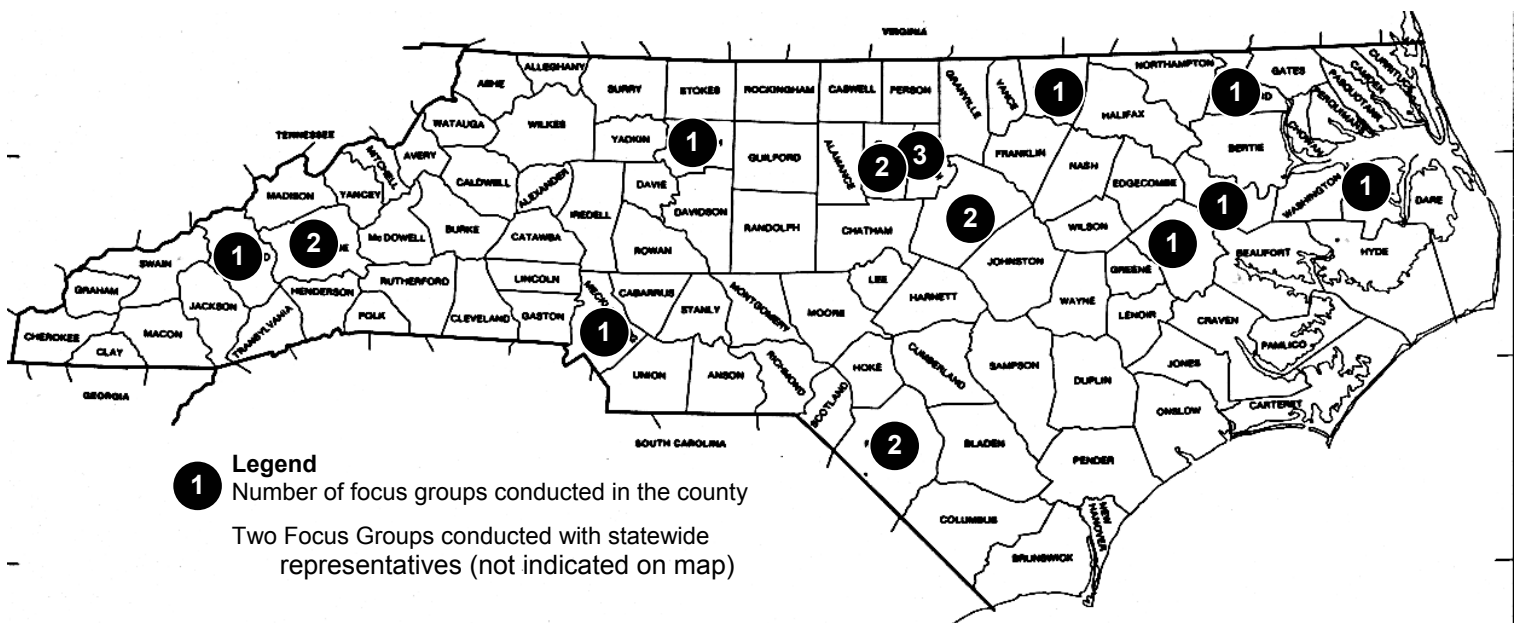


Figure 1. Geographic distribution of focus groups.

Subpopulations included in the total sample included:

- Rural African Americans
- Urban African Americans

- Native Americans / American Indians
- Latinas (fluent English-speakers)
- Low income families (urban and rural)
- New mothers
- Grandmothers and other caregivers
- Fathers
- Women with advanced degrees
- University students
- Women ages 18 through 78 years

Teams of two facilitators recruited and scheduled each focus group. Focus group participants received a \$25 gift card to either Wal-Mart or Target. Refreshments or a meal was provided (depending on the time of day). A few participants who traveled long distances (over 15 miles) were reimbursed for transportation costs. Childcare was provided when needed.

For each focus group, one team member served as the facilitator while the other served as the note taker. As part of the introduction to the focus group, all focus group participants were asked to sign informed consent forms (see Appendix F for a copy of the informed consent form) and to complete a self-report survey, which gathered demographic information (see Appendix E for a copy of the self-report survey).

The facilitator led the focus group using the interview guide. Facilitators adapted the interview guide, as needed, to each focus group so that more in depth questioning was included on some topics for certain groups while other areas were not addressed at all. The key topics covered in the majority of focus groups were:

- Defining “health” and “healthy”
- Preventative health behaviors
- Health information and advice
- Preventative health care services
- Family, friends and relationships
- Pregnancy and reproductive health
- Health disparities

All focus groups were recorded using a standard cassette recorder and a digital recorder. All recordings were catalogued and have been stored for more in-depth analysis, if resources become available. The two-person team produced a summary report for each focus group based on a report template. In addition, the focus group coordinator conducted a face-to-face debriefing meeting with the majority of facilitators. This report is based primarily on the focus group reports and the debriefing session.

Demographic Characteristics of the Sample

As part of the focus group research, we gathered demographic information from participants via a self-report questionnaire (see Appendix E for a copy of the questionnaire). A summary of this information is presented here. This information is intended to be merely descriptive as the sampling methodology for the study was not random.

A total of 204 North Carolina residents participated in the focus groups. The vast majority (95%) of participants were women (n=194). Per guidelines from the National Institutes of Health, questions on ethnicity and race were adapted from the US Census Bureau questionnaire. Thus, response categories were limited to those used in the US Census. It is important to note that many respondents, particularly those who identified themselves as “Hispanic” or “Latino,” found the distinction between ethnicity and race troubling. Many of them indicated verbally, or through marks on the questionnaires, that they do not consider themselves to be any of the races listed as response options on the form.

Table 1. Gender, Race & Ethnicity of Subjects

Race	Total		Female		Male		Missing	
	N	%	N	%	N	%	N	%
American Indian	20	9.8%	19	9.8%	1	11.1%	0	0.0%
Asian	2	1.0%	1	0.5%	1	11.1%	0	0.0%
African American	137	67.2%	130	67.0%	6	66.7%	1	100.0%
Pacific Islander	0	0.0%	0	0.0%	0	0.0%	0	0.0%
White	42	20.6%	41	21.1%	1	11.1%	0	0.0%
Missing	7	3.4%	7	3.6%	0	0.0%	0	0.0%
Ethnicity								
Hispanic	13	6.4%	10	5.2%	3	33.3%	0	0.0%
Not Hispanic	186	91.2%	179	92.3%	6	66.7%	1	100.0%
Missing	5	2.5%	5	2.6%	0	0.0%	0	0.0%

It is important to point out that the sample overrepresented African Americans who comprise 21.6 percent of the state’s population according to the 2000 US Census.

Table 2. Age of Subjects

Years Old	Total	
	N	%
18-29	93	45.6%
30-39	38	18.6%
40-49	25	12.3%
50-59	26	12.7%
60-69	6	2.9%
70 or more	3	1.5%
No response	13	6.4%

Table 3. Educational Attainment of Subjects

Highest Level Completed	Total	
	N	%
Some high school study	30	14.7%
High School diploma or equivalent	47	23.0%
Some university study	48	23.5%
Associate's Degree	13	6.4%
Bachelor's Degree	33	16.2%
Master's Degree	26	12.7%
Doctoral degree (Ph.D., J.D., or M.D.)	5	2.5%
No response	2	1.0%

Table 4. Household Income of Subjects

Household Income	Total	
	N	%
Less than \$15,000	68	33.3%
\$15,000-\$29,000	38	18.6%
\$30,000-\$45,000	47	23.0%
\$45,000-\$60,000	19	9.3%
More than \$60,000	19	9.3%
No response	13	6.4%

Table 5. Relationship Status of Subjects

Relationship Status	Total	
	N	%
Single	85	41.7%
Cohabiting	23	11.3%
Married	76	37.3%
Separated	5	2.5%
Divorced	10	4.9%
Widowed	3	1.5%
No response	2	1.0%

Results

1. Health and Wellness

All groups had a complex, well-rounded idea of health. Virtually all respondents conceived of health holistically; they connected nutrition, exercise, lifestyle, relationships with family and friends, mental and emotional health, and spirituality or religion to their definition of “health” and “wellness.” One group of Native American health care workers and educators defined health as “balance in your life,” “not only physical but mental,” and “how well you deal with stress.” Respondents frequently mentioned the need for people to be pro-active about their health by being aware of one’s own body and being sensitive to any changes. They also mentioned you can achieve good health, or better health, if you “stay on top of it” and take an active approach.

Aspects of health mentioned by groups included,

- Well-being
- Good nutrition
- Eating right
- Emotional and spiritual health
- Looking good
- Spiritual health, relationship with God
- Being disease-free
- Having energy
- Prevention of illness/disease
- Treatment of illness/disease
- Exercise
- Losing weight
- Good hygiene, being clean, keeping germs away
- Not being tired and getting enough rest
- Coping well with stress, not being stressed
- Feeling good, being free of pain
- Getting the most out of life
- Long life
- No bad habits
- Being happy
- Experiencing mental health
- Being knowledgeable about health
- Health is the most important thing behind religion
- Taking care of yourself
- Enjoying a quality of life
- Have a good attitude
- Feeling good about yourself
- Having high self-esteem

Relevant quotes:

“A healthy person is someone who is aware when she’s not functioning up to par and will take the steps necessary to take care of herself.”

“People don’t think about health until something goes wrong.”

“The key is everything in moderation. It’s okay to have a cookie one night”

“It [health] is important ... sometimes [you] can avoid certain diseases, cancer and stuff like that.”

Referring to the “right” attitude for good health, *“I can versus I can’t get myself together.”*

“A healthy person is happy all the time.”

“Being healthy is a lifestyle.”

“A healthy person is being balanced...mental, spiritual, and physical.”

“A healthy woman exercises her mind, body, and soul.”

“The older you get, the more serious you get about your health.”
“Spiritual healing is real.”
“Health is very important.”

Stress

The ability to cope and manage stress emerged as a central theme. Focus group participants from all regions of the state paid a lot of attention to stress in their lives and the impact of stress on health. Yet, there was no obvious or clear uniformity of what “stress” was or what was “stressful” although most respondents tended to focus on psychological stress and mental health. One group of African American women from eastern North Carolina linked high levels of stress to a decline in health status. For young women, particularly young mothers, personal development, or as they put it “growing up,” was a significant source of stress. For instance, facing up to the fact that they could no longer act like children since they had become parents. Numerous groups brought up the relationship between stress and pregnancy (see section on pregnancy and reproductive health below).

Relevant quotes:

“You can exercise and eat right and all you want to do, stressed out, you are not going to lose weight.”
“It [stress] can change your eating habits.”
“Stress can kill you too ... your immune system [pause] can shut down because of stress.”

Age

Another theme that emerged was the increasing importance of health as people get older. Older women tended to take personal health more seriously than younger ones. This theme emerged in two distinct ways. First, while health was a priority for all groups, younger people had difficulty (or failed altogether) making connections between their behaviors as young people and their health later in life. Younger people tended to equate youth with health or being healthy. Second, older women mentioned the increasing importance they placed on their health as they got older. One group of African American women in eastern North Carolina emphasized preventive health care as they got older and the importance of intergenerational role models.

Relevant quotes:

“As you get older, you look at health differently.”
“As we get older and have more serious illnesses we become aware of how important our health is to us.”
“I don’t think much about my health. I think that maybe in my 30’s I will.”

Intergenerational Role Models / Cultural transmission

The impact of intergenerational role models also emerged in several focus groups. For example, some groups had grown up learning the importance of health both in their own families and at school, but they found that good health behaviors were not modeled in their homes. For one group of young women (ages 19-25 years) in rural western North Carolina (all of whom were smokers), their parents had told them not to smoke, but their parents smoked. As a result, the anti-smoking messages were undermined. For women across the state from different racial and ethnic communities, they received many messages about “eating right,” but their families had

poor eating habits growing up. Most importantly, respondents of all ages mentioned the impact of fast food on their lives. (See section on nutrition and health below for additional discussion). A group of Native American health educators discussed the ways they had picked up “bad habits” from their families and parents.

Relevant quotes:

“She [my mother] has to be constantly doing something, so I think I and my sister are also a little like that. I try to think that I need to relax. Just from watching her, my sister and I picked it up.”

“Well, in my case, my mother, my mother always taught me to be clean and to take care of myself and different things. I appreciate her teaching me these things so I can pass them on to my child, cause you know that’s really where it comes from, who ever was over top of you, that will sometimes show you how you will be later on in life.”

“When I stayed with my grandmother, she ate fresh veggies. Not canned foods, I lost weight because we ate healthy.”

“My grandmother ate from the garden, things were always fresh and she would say, ‘Pop those beans right there for me baby.’” (African-American woman)

“My father always said to work hard.”

“My grandmother always said working ain’t going to kill you.”

“Older people use to say why they lived so long is because they worked hard”

“My mother always said to eat your fruits and vegetables.” (Lumbee woman)

“My grandmother baked or grilled, no fried foods, but when you eat such large proportions it adds up and all you do is sit around.”

Women’s Health

For women, health was often closely tied to their roles as mothers, wives, or caretakers. Many talked about the significance of women’s health to the maintenance of the family. For example, they highlighted the importance of setting a good example for children. Yet, virtually all female respondents discussed the fact that their health often “gets put on the back burner.” They explained they generally look at their own health last—after they have taken care of everyone else’s. Tied to this important theme were some significant barriers women faced in undertaking preventative health behaviors: time and energy.

Women from all racial and ethnic groups and all socio-economic statuses mentioned that lack of time or lack of energy made it difficult for them to do certain things they knew they should do to stay health (such as “eating healthy,” exercising, or remembering to take vitamins, among other health promoting behaviors). For different groups, these ideas were sometimes expressed in different vernaculars. For example, in some groups comprised of women of lower socioeconomic status (SES), including African American women in rural North Carolina, African American men and women in urban North Carolina, and White women in rural western North Carolina, participants cited “procrastination,” “being lazy,” and “lack of motivation” as barriers to adopting healthy behaviors.

Relevant quotes:

“Health is important but...there are some things I don’t stay right on top of. I watch over my mother’s health and my children’s, but when it comes to my own health...” (Woman in her early 20’s)

“We [women] tend to put others first.”

“If mother is sick, then everybody is sick.”

“We [women] don’t have time to get sick.”

“Health is very important, but with my responsibilities, it is hard to do.”

“I also think do good things for yourself because you are always doing things for other people.”

“My view on health changed after my baby came. Because I want to be healthy to be here and do all the wonderful things that he’s gonna do. I have to take care of myself so I can be here for him.”

“I do not leave me out anymore!”

“Women with children have to have ‘me’ time.”

Body Image

With the exception of African American women in eastern North Carolina, many female respondents tended to speak of good health almost entirely in terms of their weight. While these respondents acknowledged the importance of physical fitness, most of their discussion focused on “weight,” needing to “lose weight,” or “watching their weight.” Many women constantly felt like failures because they couldn’t lose weight. Male respondents tended to focus their discussions on exercise, eating well, and taking vitamins rather than on controlling weight.

Looking across all focus groups, it becomes clear that different racial communities have different conceptions of the ideal body type for women. Among White women, thinness is associated with being “healthy.” For many White women, this association of thinness with health is closely related to their ideas of beauty and self-worth. As will be discussed below, some obese and morbidly obese White women associated their weight gain and loss of good health with pregnancy. Likewise, the focus group of young Latina women tended to associate “health” with “beauty,” and beauty was equated with thinness for them. Much of the Latinas’ discussion related health to their maintenance of a beautiful body and figure. Among African Americans, on the other hand, a full (or round) figure is associated with good health. Thus, obese African American women did not necessarily view their weight as a health problem although many of them did recognize excess weight as a contributing factor to chronic diseases like diabetes or high blood pressure.

Body image is extremely important in understanding women’s complex ideas about health and healthy behaviors. Self-image impacts health behaviors because women who do not feel good about their bodies encounter psychological barriers, which may make adopting healthy behaviors more difficult. For example, women who feel they need to lose weight or who are trying to lose weight tend to put all of their health concerns into the “losing weight” basket. They then feel as though they are failing at good health if they do not get thin. Furthermore, for some overweight women with negative self-images they tend to view healthy behaviors as futile.

Relevant quotes:

“The biggest issue with my friends and family is losing weight - make sure you get out and exercise.”

Health Risks, Family Medical History, and Racial or Ethnic Minority Communities

For certain individuals, family medical histories played a large role in how they thought about health and wellness. In addition, among focus groups comprised primarily (or entirely) of people from racial or ethnic minorities, respondents were particularly aware of health risks or problems prevalent in their communities. Some women emphasized the importance of family medical history in how they made decisions about their health. In one focus group comprised primarily of female graduate students from the University of North Carolina at Chapel Hill, the women agreed that seeing their parents age made them more aware of the process of getting older and the need to pay more attention to their health now, while they are still young. The group also emphasized the need to be aware of and seek care for health problems that run in the family. One woman described the ways she has changed her behaviors because diabetes runs in the family.

For focus groups in racial or ethnic minority communities, health was a key concern, particularly because there are so many health problems in their communities. For example, some Native American health workers mentioned that the work they do in their community has made them particularly aware of diabetes, weight issues, and exercise. In another group from an African Methodist Episcopal (AME) church in the Triangle, which was comprised of African American women with high economic status and advanced educational degrees, the women knew first-hand the health care concerns of their community and were determined to do their part to address them. They explained that being informed about their own bodies and health care issues and being assertive with their health care providers were some the most important steps they could take toward personal health.

Relevant quotes:

“I was raised by a mom who was a diabetic.”

“Seeing my parents as they age makes me think about it [health].”

“Seeing people around me get diabetes made something click for me.”

“I tell my mom, you can eat more veggies and walk.”

“People have the attitude that ‘it will not happen to me’, so they are kinda nonchalant.”

“They feel they won’t get a certain disease, they won’t get diabetes, they have an ‘I don’t care’ attitude.”

“A lot of times close family history ... sometimes you will help you make a decision to go in to get a mammogram earlier.”

“With the older women in my family, I don’t want to be in a situation with high blood pressure. Not being healthy. I don’t want to be that way, I want to be active.”

2. Preventative health behaviors

All focus groups mentioned a wide variety of activities that promoted good health. The most commonly mentioned were nutrition and diet, exercise, health screenings, and avoiding or coping with stress.

Activities that promote good health mentioned by groups:

- Take care of the body
- A well-rounded diet
- Eat healthy foods, eat right
- Eat more vegetables
- Take walks
- Everything in moderation
- Exercise
- Maintain a healthy weight
- Sleep
- Regular doctor visits
- Regular health screenings (e.g., pap smears, mammograms, colonoscopies)
- Practice safe sex
- Take time to relax
- Take time to laugh
- Take time to do things for yourself, like getting your nails done
- Maintain good relationships with family and friends
- Avoid substance abuse
- Avoid dangerous situations (drugs, violence, etc.)
- Use common sense
- Prevent depression
- Have hobbies or creative outlets
- Stay active
- Do something (volunteer)
- Walk up and down your driveway
- 30 minutes of walking daily
- Sit down and eat (other countries eat less)
- Maintain good hygiene
- Have “me time” (time to yourself)
- Get mental health assistance (like therapy or medications) when needed
- Maintain balance
- Take a vacation
- Protective behaviors, like wearing seatbelts and sunscreen
- Follow recommended health guidelines
- Follow doctors’ advice
- Have a good support system
- Be in a healthy environment
- Avoid stress
- Knowledge about health, disease, and prevention
- Do not have a lot of babies

Many women admitted that while they know what it takes to achieve optimal health, it is difficult to consistently engage in healthful behaviors. For many groups, the bottom line was that people know what they are supposed to do to be healthy; but it is not easy to do those things because they lack the time, money, or access. While health is something many women think about regularly, they do not always make it priority in day-to-day life. Some of the barriers women face are described below in the section on barriers to adopting healthy behaviors.

Nutrition, Diet, and Exercise

A dominant theme among the majority of focus groups was the importance of proper nutrition (such as eating fruits and vegetables and avoiding fatty foods) to good health. Virtually everyone acknowledged the importance of nutrition and exercise to health, but they also admitted they frequently do not eat healthy or exercise. Some respondents (particularly older women or

rural women) said that they had learned healthy habits (like “eating fresh food from the garden”) early in life from their grandparents. Yet, they had difficulty maintaining these habits as adults.

Many respondents acknowledged the impact of the fast food culture on their habits; fast food eating habits were formed early in life. Younger focus group members explained they grew up eating fast food and they found those habits hard to change. Across all demographic categories, the bottom line was that fast food is “quick” and “easy.” For example, one grandmother, who was the primary caretaker for her two grandsons, explained that after a long day of work, it was easy to stop and get fast food for the boys: it was quick for her and she knew they would be happy. While respondents as a whole did not agree on whether “eating healthy” was more or less expensive than “eating badly,” they all agreed that fast food makes it “easy” and “inexpensive” for people to “eat badly.” In other words, fast food encourages poor food choices. In addition, several respondents said that fast food restaurants encourage people to eat greater quantities of “bad” food by offering value menus or combo meals.

Most respondents acknowledged the impact of weight on an individual’s overall sense of health. Being “too heavy” made people feel less healthy. Many older respondents also acknowledged the potential impact of obesity on health, in terms of chronic health conditions, like diabetes or high blood pressure. While not discussed explicitly, differences in ideal body size emerged between African American women (particularly those in eastern NC) and women of other races. African American women tended to conceive of healthy bodies coming in all shapes and sizes (including larger, rounder bodies) whereas other women tended to conceive of healthy bodies as being thin.

Relevant quotes:

- “My mother always said to eat your fruits and vegetables.” (Lumbee woman)*
- “Eating healthy is best, I have learned when I go to the grocery store I usually buy all types of snacks and goodies. My last time shopping, I bought all types of greens, strawberries, every kind of organic food. I bought milk and water and it only cost me \$25.00 and I had a lot of bags.”*
- “Cook vegetables, don’t dress it up with cheese and butter and all that, just plain vegetables.”*
- “I went to Paris, they ate bread a lot, it’s not what you eat, it’s your portions.”*
- “Foreign fast foods are smaller portions than American fast foods.”*
- “When you know your body, you can lose weight like that [meaning easily].”*
- “My mother made sure that we ate, but not healthy. My mother still cooks in lard.”*
- “When I stayed with my grandmother, she ate fresh veggies. Not canned foods, I lost weight because we ate healthy.”*
- “My grandmother ate from the garden, things were always fresh and she would say ‘pop those beans right there for me baby’.”*

Stress

Many respondents discussed the impact of stress on health. They explained that “avoiding stress” or “coping well with stress” were important things to do to maintain good health. While it was clear that not all populations found the same things stressful, lack of time seemed to play a major role for many people. Women said they lacked the time to do everything they needed to do. Many women identified personal time (“me time”) as an important factor in relieving stress, but could not manage to include this in their lives

While most people found managing stress to be important, very few had the techniques and skills to do so. It seemed that women of higher socio-economic status had more avenues to relieve stress than women of lower SES. For example, many of the stress-relieving activities mentioned, such as exercise, massage, yoga, vacations, etc., require financial resources. Many respondents from lower SES groups explained that they could not “relieve stress” due to financial barriers (see discussion of barriers below for more on this). Some respondents, particularly those recruited through churches, mentioned spirituality (including prayer and meditation) as an important mechanism of stress relief. Others used support groups, friends, or family to help relieve stress.

3. Barriers to adopting healthy behaviors

Many barriers to adopting healthy behaviors were mentioned, including:

- Lack of time
- Lack of motivation or will power
- Watching television (being addicted to television)
- Cost (e.g., gym membership)
- Stress and guilt of graduate students to work all the time
- Not scheduling time to exercise
- Being tired at the end of the day
- Heat or weather interferes with exercise
- Embarrassment over how other people perceive you
- Lack of health insurance
- Lack of dental insurance

The most widely cited barrier to adopting healthy behaviors among women was their multiple responsibilities as wives, mothers, employees, church members, community leaders, etc. Women say they tend to put themselves last, taking care of everyone else’s needs (and health) before their own.

Another barrier mentioned by many women was “lack of motivation,” “lack of willpower,” or “laziness.” Yet, in analysis of the focus group data it is difficult to sift these issues out from stress and depression. These barriers seemed to be brought on by negative feelings of self due to weight, particularly among white women. Thus, from the viewpoint of focus group facilitators, “lack of motivation,” “lack of willpower,” or “laziness” may be vernacular expressions of the experience of depression or of difficulties coping with stress. More research on these issues will

be required to understand how stress, depression, motivation, willpower, and “laziness” relate to each other.

Finally, many mothers (as well as other primary caretakers of young children) find they rarely have time to exercise or for “me time” due to a lack of childcare. Working mothers had childcare available while they were at work, but many did not have access (due to financial constraints) to childcare outside of work hours. Many stay-at-home mothers did not have access to childcare for financial reasons.

Relevant quotes:

“Will power as far as getting yourself off the couch or not grabbing the cookie.”

“TV is tough because it is hard to give up my shows.”

“I am embarrassed to go to the gym because everyone else is thin. I don’t want other people looking at me and comparing.”

“I will get into my car and drive across campus. I am so lazy, I will get on top of someone else’s car and ride across campus instead of walking.”

*“I put so much hard work into **not** exercising [meaning avoiding exercise].”*

“I tend to need an external reason to get back into shape like a friend’s wedding.”

Financial barriers

Virtually all focus groups discussed the complex relationship between financial constraints and healthy behaviors. Participants from lower socio-economic backgrounds or households mentioned numerous ways economic constraints limit their adoption of healthy behaviors. For example, several respondents discussed that gym memberships and exercise classes cost money.

The majority of respondents highlighted the complex relationship between economic constraints and people’s choices regarding food. The themes of economic struggle and poverty dominated the groups’ discussions of health in two focus groups comprised primarily of low income African Americans in Durham, NC.

Relevant quotes:

“Don’t you know that cost money (gym)?”

“You may not have the resources that other people have, then when you go to the grocery store, you might not can buy the regular cut meat that prevent obesity. You may have to buy the meats that have more fat because it tends to cost less.”

“Even though they[healthy foods] aren’t cheap, there is easy access.” Statement from a woman who lives in Chapel Hill, NC

“When you are feeding a family, you may have to make some decisions not necessary based on health.”

Time Constraints

Many focus group participants indicated that lack of time made it difficult for them to eat right, exercise, or have leisure time (and relieve stress). Several respondents from low income households linked their financial situation with lack of time and stress. For instance, being forced to hold multiple jobs to make ends meet.

Relevant quotes:

“Having a different type of job (for example) if you make \$77,000 a year, you’re not running out looking for a second job.”

“There’s a day job, night job, a part time job.”

“If I can’t make it [a meal] in 30 minutes, we’re not having that...I do things ahead of time.”

“Everybody running in doing something quick, not having the time to prepare the meal or having the time to grill.”

“Running down behind children is enough exercise.”

4. Things that promote healthy behaviors

Focus group participants mentioned a wide variety of factors that supported them in adopting healthy behaviors. In particular, they mentioned:

- Access to healthy foods (“even though they aren’t cheap, there is easy access.”)
- Having dogs as pets promotes regular walking
- Family support
- Good relationship with healthcare provider
- Stable environment (housing, employment, family, relationships, etc.)
- Empowerment

Family Support

Many of these factors seemed to be largely idiosyncratic, but a few common themes emerged. Women (and men) reported that when spouses play an active role in supporting healthy behaviors, it is much easier to adopt (or continue) them. Spousal support seemed to reinforce healthy behaviors in two ways. First, it helped people keep healthy behaviors in mind or as an external mechanism of discipline and individuals felt nurtured and cared for by their spouses when they took an interest in their health. This theme was slightly different for female and male respondents.

For female respondents, spousal support for healthy behaviors was key. Women widely reported that husbands’ or partners’ involvement in their health care choices made a big difference. For instance, women (and men) reported that they felt much better when their spouses accompanied them to the doctor. Having the emotional support from their spouse made them feel good about visiting the doctor and taking care of their health. Respondents in one group of African American women from Robeson County explained that men’s attitudes affect women’s decisions in receiving medical treatment, even when these attitudes are not explicit.

On the positive side, when husbands (or boyfriends) remind women about their health behaviors, it made the women feel cared for and nurtured. For some women, very simple gestures, such as reminders to take a vitamin or to eat vegetables, from husbands or boyfriends provided substantial emotional and psychological support for the women’s health choices. Some mothers highlighted that without support from their husbands the women would have little opportunity to adopt healthy behaviors. For example, a husband taking care of the children so that his wife could have some “me time” or go to exercise.

Relevant quotes:

“My dad kept my mom healthy.”
“I grew up in the gym; my father would let me go. They had a kid’s gym. I would go to the kid gym every time he went to the gym, like Saturdays. My dad really helped me out like health wise, when he ran, I would have to ride my bike beside him.”

Male respondents explained that they avoid going to the doctor “unless something is really wrong.” Even then, they are unlikely to go unless the women in their lives (usually mothers or wives) “force” them to go. Several women complained the men in their lives have not taken an active interest in seeking health information and services. As a result, women have assumed the roles of caregiver and health steward. Many women shared stories about asking and reminding their husbands to take preventive health measures or see the doctor. One woman shared how she grew up in a family where medical care and health was very important, and trying to relay the importance of health to her boyfriend. Another explained that her husband had not been to the doctor or dentist for 10 years when they first met.

Relevant quotes:

“I was also helping him, but my health was suffering.”
“My boyfriend won’t go to the doctor unless he is dying.”
“Your wife got to make you go (to get check ups).” (Male)
“I won’t go to the doctor. My wife made me go and I found out I have diabetes.”
(African American male)

Stable Environment

A second common factor that emerged was that a stable environment and stable relationships help to promote healthy behaviors. Stable environments include physical, economic, social, and mental factors. Stable relationships include romantic relationships (whether with spouse or other partner), familial relationships, and friendships.

Relevant quotes:

“Everyone being on the same page and [getting along].”
“Having a good relationship [with family] is an important thing.”

Relationship with healthcare provider

Another important factor was a good relationship with a doctor or other health care provider. A good relationship comprised many different things, but most importantly it was a relationship of mutual respect where the patient felt like the health care provider truly listened to them. Another important component of a good relationship was having a consistent health care provider who saw them over time. Respondents who received most of their health care in community clinics, public health departments, or emergency rooms frequently cited “bouncing between doctors” as detrimental to their health care and specifically to preventative health care. Particularly respondents who received Medicaid benefits emphasized that they had difficulties due to being shifted between various health care providers.

Empowerment

A final common theme that emerged was having a sense of empowerment. Empowerment may seem to be a nebulous concept, but in the course of this research several concrete factors emerged. Being able to ask questions of health care providers was particularly important. For instance, several African American, American Indian, and Hispanic respondents explained they are sometimes reluctant to ask health care providers questions for fear of being treated disrespectfully by nurses or doctors. More about the role of empowerment in health and healthy behaviors is discussed below.

Environment

Focus group members from the University of North Carolina at Chapel Hill noted some features of the university community that promote healthy behaviors. For instance, walking is built into using Chapel Hill's bus system. In addition, being on a university campus where parking is difficult encourages walking. Finally, the student health service, where most services are "free" (meaning they are included in the required fees students pay each semester as part of their tuition and fees), makes health care financially accessible.

Relevant quotes:

"I purposely live close to campus so that I can walk and get exercise- I do walk a lot"

"I have two dogs, so I walk at least 2 miles per day."

5. Health Information and Advice

Focus group participants use a wide variety of sources for health information and advice.

Sources mentioned include:

- Internet
- Rely on myself
- Health educators or community health liaisons
- Health professionals (doctors or nurses)
- Family members, friends or colleagues in health care or health education
- Books
- Magazines
- TV shows
- Television advertisements
- Peers or friends
- Older women
- Family members

Many respondents reported being very proactive about researching information about health concerns whenever something is "wrong" (i.e., they have a health problem). They talked about their tendency to research a health problem or ailment before going to the doctor, so they are well informed and prepared with a list of questions. Overall, they researched and consulted a few sources, weighed the information and then determined what steps to take.

Respondents all had their own idiosyncratic processes for seeking health information. However, a typical process for handling a health care question might be to ask reliable friends or family members about it first, follow up with some research either online or in books, check with the

accessible health care avenues, such as friends or family members who are health educators or nurses, then finally, if the question persists, to make an appointment with a doctor.

Virtually all groups mentioned the Internet as a source of health information. A notable exception was that the two groups recruited from public housing in Durham did not mention the Internet as a source of information. In general, respondents mentioned that they relied on established websites, like WebMD or Dr. Koop, and websites for professional organizations or specific health issues, like the American Medical Association or the American Diabetes Association.

Many respondents mentioned health-related television programming (such as The Learning Channel, Discovery Channel, Discovery Health, etc.) as a primary source of health information.

Most people explained that they used doctors as a last step in the information process. For some this practice was a matter of practicality, a visit to the doctor required time and money so it could not be done for “frivolous” reasons. Another important factor for certain respondents was that they do not always trust doctors. Some respondents had bad experiences with doctors making wrong diagnoses in the past, as a result they do not trust physicians. Some African Americans mistrust the health care system in general due to the lasting legacies of segregation, the historical mistreatment of African Americans by the medical establishment (respondents specifically mentioned Tuskegee and eugenics), and the persistence of discrimination among physicians (see below for additional discussion on this topic).

Access to community health educators or community health resources impact people’s health choices and influence women’s thinking about health. For groups recruited through community health educators, participants frequently mentioned the health educator as an important source of information about health or childcare. In addition a few groups mentioned health seminars, either through the public health department or local churches, as sources of information about health and healthy behaviors.

Relevant quotes:

“You know how you feel. Being assertive about your own health.”

“If you don’t know what you got to do, you can’t do anything.”

“You have to know about health to be healthy.”

“There are so many mixed messages that it is best to do my own research.”

“I make my own health decisions but if it’s something major, I ask my mom and she can ask the doctor because she is a nurse and works at a clinic.”

“I try to go and see what is already out there before getting to the doctor.”

“Anytime I have a problem I look it up on the Internet.”

“We take it [information] to the doctor and we already know what to tell them [about what is going on with their health].”

“It’s always good to call them [doctor’s office] to verify information you read online.”

“I looked up breech birth on the internet.”

“I read a lot of books on pregnancy.”

6. Preventative health care services

Virtually all respondents acknowledged the importance of using preventative health care services, like health screenings or wellness visits. Yet, most respondents acknowledged that they only visit a health care provider when an illness or health crisis precipitates it. This concept was frequently expressed through the refrain, “If it ain’t broke, don’t fix it.” One exception is parents (and especially mothers) of infants or young children who went regularly to well-baby appointments and made sure their children were vaccinated.

Relevant quotes:

“If it ain’t broke, don’t fix it.”

“I take it [my health] for granted. I’ve always been healthy.”

“If you’re not hurting you figure you’re healthy...everything’s clicking.”

“When your medicine runs out you got to go [to the doctor].”

“It’s a last resort for me—I will go in when I feel bad.”

7. Barriers to preventative health care

A great deal of the discussion focused on the barriers people faced in accessing preventative health care services. Many people noted that fear or denial keep them from going for health screenings, like mammograms or colonoscopies. The reported fears were diverse ranging from fear of certain procedures and pain caused by procedures to fear of the test results (i.e., “finding out something is wrong”) to fear of disrespectful treatment by health care providers (see below) or fear of misdiagnosis (see below.)

Again time was a factor for several respondents. Some respondents reported difficulty in scheduling appointments at convenient times or within an acceptable timeframe or getting time off from work for appointments. When they did go for an appointment, many respondents encountered long waits in the waiting room or exam room. For those who use free clinics, community clinics or public health departments, the long waiting times to see a doctor was mentioned by virtually everyone. In one focus group comprised entirely of men, they explained that there is a two or three hour wait at the free clinics and “men won’t wait.” This lack of timely and efficient service makes it less likely for people to seek preventative health care.

Focus group participants from rural areas, particularly in eastern North Carolina, reported a lack of available health care services. Some doctors are not taking new patients so it is difficult to find a doctor. In addition, the lack of doctors results in a limited choice for patients. Several respondents indicated that since they can only access specialists through their primary care physicians, the respondents do not use all recommended preventative health care services. For instance, a woman who wants a mammogram must first get a referral from her primary care physician, which adds an additional step (requiring, time, money, transportation, etc.) to the process. Finally, respondents from rural areas indicated that lack of transportation and the distance of health care facilities could be a problem for people without their own cars as well.

Relevant quotes:

“I don’t like to go to the doctor; I have a phobia ... scared they will find something?”

“My friend was throwing up and they gave her pills for anti nausea- the pain got worse; the next day, they told her she was okay then she went back and they found out it was intestinal blockage- had to push for it.”

“Pain is a factor because my cousin talks about the mammogram; and the GYN exam isn’t bad, but it’s not fun.”

“I had to go to the dermatologist to get my birth mark off my face and it turned out horrible and a bruise and swollen- doctors not telling you what to expect.”

Financial Barriers—Lack of Insurance or Limited Insurance Coverage

Virtually all respondents noted financial reasons that prevented or delayed their accessing preventative health care. Respondents without insurance and who pay for health care out of pocket said that they frequently delay getting health care screenings, like mammograms or colonoscopies. Yet, it was unclear from the focus groups whether people without insurance or poor insurance make fewer visits to health care providers. Some respondents with insurance indicated that co-payments, particularly for medications, limited their use of health care services. A focus group comprised primarily of African American fathers from the Winston-Salem area discussed the overall lack of knowledge about free health services that are available to those who may have difficulty paying for health care. They noted that minorities do not often have the time or perhaps the means to research health resources (i.e. clinics, public health department vaccinations, etc.)

Relevant quotes:

“You have to be discriminant about what services you get [due to cost].”

“I am due for a dental check-up, but I am not going because I don’t have insurance.”

“It would be nice if there was a cheaper coverage than HMOs, and alternatives; then you could have a relationship.”

Medicaid recipients

Virtually all Medicaid recipients believe that they do not get same level of care as those with private insurance. Many participants discussed that having Medicaid may be deciding factor in how much attention and the quality of care you receive from the health care professional. One woman mentioned that because she was on Medicaid, she felt she was treated as if she were stupid and did not know anything.

Participants attributed these differences in care to many factors. First of all, many perceive that Medicaid limits the procedures or medications that health care providers can give patients. Second, they feel that health care providers or support staff at health care clinics do not treat them with respect or have preconceived notions of who they are and how they behave. Respondents from racial or ethnic minorities explained that frequently they feel as if their race or ethnicity influences the ways that health care providers or support staff treat them. Finally, Medicaid recipients reported they are not allowed to see the same health care provider at each visit. As a result, they do not build relationships (and trust) with their health care providers. They emphasized that this situation undermines care. One woman explained how a physician gave her a glucose tolerance test when another care provider had already diagnosed her with gestational diabetes. When she told the physician she should not have the test, he refused to listen to her because he could not find it in her chart.

Relevant quotes:

“If you have insurance, you get the utmost treatment. It depends where you’re at.”

“My kids have Medicaid and it takes forever to get an appointment; and you have to wait so long.” [Mentioned having to wait once from 9 a.m. to 4 p.m. to be seen].

Attitudes of health care providers

Virtually all respondents highlighted the influence of health care providers’ attitudes (and the health care system more generally) in whether or not they sought preventative health care. Among respondents who feel empowered to navigate the health system, good and bad experiences with health care providers had a significant impact on their attitudes and beliefs about health care. Respondents with good, trusting relationships with their health care providers reported that this relationship made it easier for them to get health screenings and tests. For those respondents with negative experiences with the health care system, whether misdiagnosis or disrespect from a health care provider or support staff person, they reported having an added psychological barrier to overcome before scheduling an appointment for a health screening or wellness visit.

A primary theme that emerged was poor communication with health care providers. Some respondents cited cases where health care providers did not explain what they should expect from a procedure or illness. In other instances, people recounted situations where physicians did not speak to them in a way where they could understand what the physicians were saying. Most significantly, respondents highlighted that it was very frustrating when doctors or nurses did not seem to listen or pay attention to what the patient was saying.

The places where respondents received most of their health care services seemed to influence their perceptions. Respondents who used public health clinics or who were Medicaid beneficiaries felt as if support staff and health care providers treated them disrespectfully. Several respondents, particularly those in eastern North Carolina, reported that they had received poor medical care and encountered health care providers with negative attitudes in Emergency Rooms.

Many respondents indicated that they felt as if the doctors rushed them in and out of the examination rooms. As a result, they did not feel free to ask the doctor questions so preventative health care services sometimes fell off the list of issues they discussed with their doctors.

Not being treated with respect by doctors was particularly problematic for older or poor or uneducated women. Younger women were more likely to ask their health care providers questions so they got better treatment. Many older women grew up in an era when doctors were seen as gods. Thus, these women did not feel at ease questioning the doctor or his recommendations. Finally, doctors sometimes assume certain patients (whether poor, uneducated, African American, or some other characteristic) are unfit or dumb or unwilling to change their behavior.

Focus group members in rural areas noted that there are some confidentiality issues in seeking health care. People fear being seen at a specialty clinic because it might start rumors about them. For instance, a Lumbee woman said that she avoided going to the clinic on the day of the week when new obstetrical patients are regularly scheduled.

Relevant quotes:

“You don’t get the adequate care in going to the doctor because there trying to rush you out.”

“I don’t like when they rush you.”

“You wait and then they don’t really take their time with you.”

“You wait an hour then you have a three minute appointment”

“They just want to walk in, get in and get out”

Physicians created negative feelings by *“Not telling you what is going to happen.”*

“It makes me feel as if I am being judged in a negative way.” statement from an African American woman regarding a doctor’s behavior with her.

“You come out feeling the same and then they give you a bill for \$2,000”

“Doctors should care about people that come in, instead of getting you out as quick as the can”

“I feel disappointed in our medical system.”

“We pay so much for health coverage, and generally don’t get much health care.” (Female with private insurance)

“They [hospitals] don’t see people as people they see people as beds... They wanted me to sign the DNR [do not resuscitate] papers.” [said in reference to his experience with his mother in the hospital.] (Male)

“I used to work on the hotline (ASHA) warning people about STDs. It made me question the doctor when callers called. They would say something that the doctor said and it sounded like the doctor really didn’t know. It made me wonder. Doctors should have been a little more factual.” (African American university student)

“I said I was a virgin and she (nurse) actually started laughing!” (African American university student)

8. Things that promote use of preventative health care

Focus groups also discussed things that promote use of preventative health care services. Most important were good experiences with the health care system and health care providers.

Positive experiences mentioned include:

- Going to the doctor and having them spend a lot of time with you
- When the health provider is attentive and listening
- When the provider takes the time to review chart and recognize problem (i.e. looking out for something because it runs in the family)
- Positive reinforcement (e.g., dentist saying something positive about teeth) can lead to feeling empowered
- Having good exams—no pain, no embarrassment
- Good doctors and nurses who have good people skills

- When they are smiling and talk to you
- Nice environment
- When they listen

Many respondents recounted stories of physicians or nurses who had provided exemplary health care. These stories generally hinged on a few core experiences including, a care provider taking time with you, a care provider listening attentively, and a provider reviewing your medical history and recognizing a problem or health risk. Many (but not all) women reported that they preferred to see female doctors. They indicated that they felt as if female doctors treated them with greater respect and empathy.

Relevant quotes:

Successful appointments hinge on the attention and openness provided by the doctor. *“It’s the attention that you get and if you feel that you’re being heard.”*

“I see my private doctor once a year.” Stated as an affirmation or illustration of a good relationship with a health care provider.

“I notice that female doctors are listening more and taking their time and there is a big difference.”

“I switched doctors and found that the appointment was much better and she knew that I was apprehensive, so she took her time.”

“My first gyn experience was with a male doctor. He was a resident and was more patient and nervous than I was, so it made a difference because of the attention.”

“I will go to my doctor when I’m 75. He treats me very nice. When people go the doctor and have to pay for a prescription, my doctor gives me the full prescription”.

“My doctor will have you come in until he finds out what’s wrong with you and if he can’t he will send you to someone who can.”

9. Family, Friends and Relationships

From the focus group data, the impact of family and friends on people’s health care choices is significant. Many focus groups discussed the ways that the relationship you have with your family can affect your health by either elevating or reducing stress. In addition, the family can support healthy behaviors. Many parents highlighted the ways that they try to set a good example for their children by eating right or exercising. One father explained how he started a tradition of exercise and being healthy for his family. He said that his family, and particularly his children, helps keep him motivated.

In some instances, families can provide an unhealthy environment. For example, an African American woman talked about how her family uses food as a way to get together and socialize. She explained that it was not necessarily healthful as much of their family time centers around unhealthy foods (i.e. cakes, cookies, fried food).

Particularly for women, choices regarding health are strongly influenced by their relationships with family members, the ways they were raised, and their relationships with friends. As

discussed earlier, women reported that husbands' or partners' involvement in their health care choices helped the women to make healthy choices.

In addition, a network of supportive, positive people can greatly enhance health. For many women a support network is essential (goes back to idea that health does not just concern the physical). Women frequently sought advice or emotional support from friends regarding health and healthy choices. Friends were frequently a trusted source of health information, particularly for women who were pregnant or who had young children.

Pregnant women and new mothers reported that rocky relationships during pregnancy increased the stress in their lives. This form of stress crossed class, ethnic and racial lines. The focus group research strongly suggests that difficult marital or romantic relationships may undermine health choices. Some young mothers felt their parents were judgmental because they were young and pregnant. Thus, they sometimes avoided telling their parents about their pregnancies until the pregnancy showed. For some women, this situation delayed their seeking prenatal care.

Many respondents indicated that family medical histories impacted their decisions about health. Some respondents who saw older family members (usually parents) develop chronic diseases like diabetes or heart disease reported that they began to pay more attention to their own health. Similarly, respondents in their 20s or 30s who had begun to see their parents "slow down" began to pay more attention to their own health choices in the hopes that they might avoid similar problems.

Relevant quotes:

"I bug my mom about her health."

"My dad died from cancer, he was a smoker. My grandmother died from a heart attack and she was a smoker. My mom is overweight, so genetically, I'm in line."

"I need to cook more healthy [for my children]. I make sure they [the children] get greens ... beans...I want to be around for them cause I'm all they got."

"It's [burden of disease and death on both sides of family] created a whole new environment in terms of eating, it's a whole different experience in terms of diets."

"With my children, I want to eat better and exercise so I can live longer to see my kids and grandkids."

"I see health issues in my family and think of ones that I can prevent."

"For health decisions I ask my mother, my mother know everything"

"When I go home, my mother gives me a lot of food but at the same time she says that I am fat- you are doing two contradictory things."

10. Pregnancy and reproductive health

Across the board, pregnancy changed women's attitudes toward their health. Most women reported they tried to do everything right once they learned they were pregnant. Many sought early prenatal care although there were significant exceptions (most notably among younger women who were hiding their pregnancies from parents.) Yet, many mothers indicated that they had trouble achieving completely healthy behaviors. Particularly, women who smoked found it very difficult, if not impossible, to quit smoking.

When asked what makes a “healthy pregnancy,” respondents mentioned the following:

- Emotional support and well-being
- Being stress-free and happy (not depressed)
- Taking prenatal vitamins
- Resting
- Being active
- To be surrounded by people who care for you
- Not being restricted unless there is a major medical problem
- Supportive relationship with doctor
- Everything going well
- Healthy baby
- Quick recovery
- Taking vitamins or iron pills
- Good preparation
- Educating yourself about pregnancy
- Avoiding danger
- Learning to re-adjust
- Thinking less about yourself
- Having perspective
- Standing up for yourself—don’t want to get run over by others
- Learning to take charge
- Pregnancy goes to 36 weeks or more
- Baby is over 5 ½ pounds
- Not in labor for a long time

Relevant quotes:

A health pregnancy is *“A glowing pregnant woman.”*

“They got so much attention because they were pregnant.”

“My image of a healthy pregnancy is where women maintain their body type, but just have a big belly.”

“My friend wants to fix all of her health problems now before she gets pregnant next year.”

You always hear, *“Get in shape so that you can get pregnant.”*

“I owe my child good health – bringing a child in the world who did not ask to be brought into the world.”

“A healthy pregnancy is having a positive attitude, no health problems with the baby or yourself.”

“Baby could come up with something if you don’t think about your health”

Women cited a healthy relationship with their partners as an integral part of a healthy pregnancy. Yet, for some pregnant women partners caused a lot of stress. Many women reported that their husbands (or boyfriends) did not understand what they were going through. As one woman put it, “they want to be the baby.” Difficulties in the relationship with the fetus’s father came up in

more frequently in focus groups with African American women and with lower, income women of all racial backgrounds. In a focus group with WIC mothers in Haywood County, the stresses of teenage pregnancy were linked to difficult relationships with the babies' fathers or conflicts between their families and the babies' fathers. One woman explained that during her first pregnancy her husband cheated on her, which "was very stressful." Another woman explained that her father "wanted to kill" her husband (her meaning appeared to be literal) and so she could not maintain a relationship with her husband and her own family simultaneously. Among the few focus groups comprised predominantly of affluent, white women, this issue was not raised.

Relevant quotes:

"Being a single mom, I worry about the future, not having enough money."

"It's hard to be married, too, sometimes."

"I wanted the father of my baby to come [to the birth]; my mom wouldn't allow him." (White female in her 20s who first became a mother as a teenager)

"The father of the child was a lot older and he was in prison- a lot of factors made it stressful."

"The relationship with the partner is so important—if you don't have someone there, you take it out on someone else when you are upset."

"My dad wasn't there for her so she felt pretty depressed."

"I wanted the baby's father to go away so I could have it to myself; but you have grow up."

"Men did everything, got you pregnant then want to go out when they want to and you have to stay home. They ask stupid questions, they be there when you don't want them to be and when you want them there, they were gone"

Likewise, some of the male focus group participants acknowledged that pregnancy created stress in spousal or boyfriend-girlfriend relationships. For some, an unwanted pregnancy could generate stress because of the economic concerns it created. A focus group of primarily African American fathers who are members of a fathers support group explained that many women worry whether the father will stay with them, so they may act "mean." Other insecurities of a pregnant woman, such as looks, could also create difficulties in the relationship. Some men listed ways to be supportive of pregnant women and new mothers. A few men indicated that they see other men (fathers, husband, boyfriends) who are at a loss as to how to behave or what to do to "be supportive."

Relevant quotes:

"Always let her [pregnant woman] know she looks good to help build esteem."

"First of all, she's looking at you." because you got her pregnant.

"Questions about whether you're going to be there for her." can cause pregnant women stress.

"Man gets stressed about how you're going to support [the baby]; [these are] thoughts and concerns, [they are] not meant to be intentionally hurtful."

In the old days a new mother was not allowed out of house for 30 days, "you just had to do it. When the baby cry, I get up."

"Let her rest and you take care of the baby."

When my wife was pregnant or nursing "she had a list like this...[gesture showing a long list] who do you want me to take care of the baby or you?"

[In response to a question about what things a woman should not do while pregnant but does anyway] *“Talk bad to me.”*

[In response to a question about what makes a healthy pregnancy] *“Stay out of swinging reach of the mother.”*

Nearly universally, respondents discussed the stress that can accompany pregnancy and childbirth. Sources of stress named included issues with spouse or family members, drug abuse, financial concerns, lack of information and support, and the competing demands of work and family. For women who had experienced miscarriages or fertility problems, the process of getting pregnant generated a great deal of stress. Once they became pregnant, some women constantly worried whether the baby would be healthy. A few women highlighted they made healthy choices during pregnancy to protect the health of their babies, but they found it frustrating that sometimes things can go wrong even when the mother does everything right.

Many young mothers who participated in the focus groups described how they found that during their pregnancies their roles as mothers-to-be generated a great deal of stress. They cited many reasons for this. For instance, being forced to “grow up” during their pregnancies to prepare for motherhood or worrying about their skills as parents. Many new mothers highlighted the challenge of developing a relationship with their partners. Young mothers also highlighted their ambivalence towards their own mothers during pregnancy and just after childbirth. Many young mothers simultaneously felt nostalgia as they faced the fact that they would no longer “be the baby” and desired to cut the apron strings with their mothers.

Respondents listed numerous activities that support having a healthy pregnancy, including:

- Taking prenatal vitamins
- Resting
- Being active
- Eating right (not overeating and not having caffeine)
- Not gaining too much weight
- Being aware of gestational diabetes and stuff like that
- Taking yoga and walking
- Having a supportive partner (mention of domestic violence issues related to pregnancy)
- Prenatal care
- Taking time for yourself
- Getting pedicures
- Shopping
- Researching everything
- Seeking support to reinforce healthy behaviors
- Not smoking
- Taking childbirth classes
- Be sexually active
- Drink plenty of water

Respondents also noted activities they themselves did while pregnant or that they saw others do while pregnant:

- Having a glass of wine
- Overexertion (heavy lifting, for example)
- Smoking or being around people who smoke cigarettes
- Painting bedroom
- Not doing something for themselves to relax
- Denying they are pregnant
- Going out, partying
- Working too much
- Pushing self too hard
- Excessive worrying

Relevant quotes:

“I regret smoking when I was pregnant.”

“When I was pregnant, I laughed a lot and enjoyed life.”

“The whole idea of eating for two is taking it too far sometimes.”

Many groups emphasized the particular pressures placed on working pregnant women. For instance, a few women explained that they had been forced to hide their pregnancies as long as possible in order to avoid problems (such as discrimination) on the job. A few women explained that they had encountered difficulties finding a job when they were pregnant. Employers did not want to hire a woman who was pregnant or who might have children.

Overall, pregnancy was an opportunity for women to get more healthcare information and to take a great interest in their health. Pregnant women become more health conscious, more concerned with eating well, keeping a healthy weight, avoiding alcohol and other things that might harm the baby. For many women, pregnancy was their first encounter with holistic health care. Those who enjoyed these experiences yearned for relationships with their primary physicians such as the ones they had with their midwives or OBs. In addition, they felt that they had had easy access to health information. This situation improved their health in general and, for some, changed their attitudes toward health and health care.

Relevant quotes:

“It’s frustrating because you can do everything right and it [a pregnancy] can still go wrong.”

“My mother told me what she went through; sometimes it’s [pregnancy] aggravating.”

“I became a hypochondriac, the doctor got tired of me. The baby had hiccups and I thought the cord was around its neck.”

“Midwives provided the best kind of health care I’ve had. They were knowledgeable and really used holistic medicine.”

[Referring to the midwives’ care] “That’s what you call options. You don’t get that if you’re in a clinic. They tell you what you have to do.”

“I want my mother there, when I have my baby.”

“The birthing rooms are very warm and comfortable.”

“I wanted my mother to be in the labor room.”

Some White women highlighted pregnancy as the beginning point of their “weight problems.” The women who discussed this had gained excess weight during pregnancy and had been unable to lose it afterwards. For some of these women, their excess weight gain was very substantial—more than 150 pounds. These women associated pregnancy with their loss of “good looks” and with the beginning of ill health, as well as discrimination, related to obesity. Many obese women cited their obesity as a factor that generated ill treatment by health care providers. They explained that health care providers perceived them as “stupid,” “uneducated,” and unwilling to change their health behaviors.

11. Race, Ethnicity, and Health Disparities

Numerous focus groups directly addressed the issue of health disparities between different racial and ethnic communities in the state of North Carolina. Usually, facilitators presented some statistics comparing rates of infant mortality between different racial or ethnic groups both for the entire state of North Carolina and for the local community. In some groups, facilitators also presented information regarding general health disparities between Whites and African Americans across the state (information comparing other racial or ethnic minorities was not available to present).

The sampling methodology specifically selected certain focus groups to be entirely or predominantly composed of a single ethnic or racial minority. In these focus groups, participants frequently felt more at ease discussing issues related to ethnic or racial difference.

Race and ethnicity presented a significant barrier to health care services for many African Americans, American Indians, and Latinas. Members of all three groups felt as if their race or ethnicity created negative preconceptions with many health care providers. These preconceptions made it difficult for them to develop a relationship with their healthcare providers. In addition, membership in a racial or ethnic minority generates stress for virtually everyone. Several respondents indicated that the lack of an advocate could be a factor in health disparities for minority communities. The power relationships between patient and health care provider can create situations where the patient does not feel like she can advocate for herself and where no one else will advocate for her. Another factor frequently mentioned was that minority patients frequently must seek care from providers of a different race.

Relevant quotes:

“For someone who isn’t assertive or knows what questions to ask, there are assumptions.”

“Going into a practice where the doctor may not be of the same race”

“Being talked down to or being treated differently compared to when a white woman walks in.”

“If you don’t know the questions to ask, providers may not tell you everything.”

“I see each race struggling with children; I see equal amounts of the issue.”

“Our country stresses us out!”

Below, an overview of the perspectives for different racial or ethnic populations is provided. Notably, there were some significant differences between African Americans in eastern North Carolina and the rest of the state.

African Americans

This research included a robust sample of African American voices from across the state. African Americans of all socio-economic statuses and educational backgrounds were included. Many African Americans included in the focus groups had had direct experiences with segregation and its impact on health and health care. For some, these past experiences may have helped to highlight how much “things have improved.” Nonetheless, there was a widespread perception among African Americans that physicians do not give them the same treatment as whites. They perceive that they wait longer to be seen than white patients, and they believe that doctors give white patients different (presumably better) prescription medications to treat their illnesses. For most, these perceptions were based on negative experiences with health care providers and with the health care system.

Virtually all African American participants reported negative experiences with health care providers and with the health care system. While many of these negative experiences mirror those of White respondents, they were more numerous among African American respondents. Some common themes that emerged were difficulty communicating with the doctors, lack of consistent health care provider, and long wait for appointments in medical clinic waiting rooms. Many African Americans reported that doctors talked down to them or did not explain things sufficiently for them to understand. In addition, some doctors have poor “bedside manner,” which makes it difficult to communicate with them. A widespread complaint was the rushed manner of doctors during examinations. As a result, many African Americans reported that they did not develop good (trusting) relationships with their health care providers.

The story of one African American man illustrates the connection between minority and socio-economic status. He explained that he used to go to a white doctor, but then he transferred his medical records to a local African American doctor. When asked why, he explained that he did not trust the original doctor because “I saw negative things happening.” He described seeing Medicaid patients being poorly treated in the medical practice. Although he had private insurance, he “felt bad for the other people [Medicaid recipients],” and left the practice.

Better education or higher socio-economic status seemed to make it easier for certain African Americans to advocate for themselves in the health care system. A story told by a highly educated African American woman in Carrboro, NC illustrates this point well. She explained that more than once she had encountered doctors who failed to address behavioral changes (such as changes in diet or exercise) as part of her treatment plan. When she questioned them about it, they said that they “knew she wouldn’t change [her behavior] so why bother?” She resented their assumptions about who she was and how she took care of herself. Given her sense of empowerment, she continued searching for a doctor until she found one who treated her with respect.

Relevant quotes:

“Sometimes we [African Americans] don’t take having a baby as seriously as we should.”

“We struggle us black people all our lives.”

“You’ve got to do what you got to do to survive. Give me a job, I’ll work it.”

Statement from an African American participant from a very low income community in Durham, NC

If you are “minority, the only time you go is when you need to, when something happens to you or someone close to you.”

“Fear of what the doctor might say causes one not to go to the doctor.” (African American from Robeson County)

“When you go to the hospital and wait forever, you come out feeling the same way. I want to feel better when I come out.”

“Doctors should care about people that come in, instead of getting you out as quick as the can.”

“When doctors use words that I don’t understand, I say, “be ghetto” with me and break it down, but he don’t. I leave it alone and come home and ask someone.”

“...if you go there, you be sitting there for hours, when you just want to go there to get seen and come out, that make you not want to go.”

“I don’t understand half the time what my doctor is talkin’ about.”

“He talks fast, I ask the lady in there with him. What in the world is he talking ’bout?”

“Just their bedside manner ...some doctors are just nasty and then you have some with good bedside manners and that’s positive...”

“Some of um [doctors] act like they don’t want to talk to you, you got to be forceful about it.”

“You play musical chairs, you go in, you sit here and then you sit there for a few more minutes and then you go in a room and you sit there for a little while, they come in and check you and they say they will be back...it takes a long time.”

African Americans in eastern North Carolina seemed to have more widespread experiences of explicit racial discrimination both in the traditional health care system and in daily life. As one focus group facilitator put it, “a sort of plantation mentality” still exists in eastern North Carolina. Highly educated African Americans are perceived as exceptions in eastern NC and Blacks who “ask a lot of questions” or otherwise “cause trouble” are labeled as “uppity.” In this context and given the legacy of segregation, some African Americans (particularly the elderly) are reluctant to ask questions of health care providers or to otherwise advocate for their health. They were trained to be deferential to doctors (“we treated doctors like gods”). Many respondents in eastern North Carolina indicated that they obtained health care outside of their county of residence due to a host of negative experiences with local health care providers.

Relevant quotes:

“My grandmother who passed away did not have a lot of knowledge about it, so, usually when she went she would take me with her and I would ask a lot of questions for her, I guess...I don’t know if she had bad experiences with them or she didn’t want to talk to them, I don’t know what the reason was...”

African Americans perceptions of the health care system extended also to health care research. Many African Americans, particularly those in eastern North Carolina or of low SES, questioned the validity of statistics and methodology behind the research that supported the notion that Whites have better health status or pregnancy outcomes than African Americans. Directly

related to this issue of negative perceptions, many African Americans highlighted that there is a shortage of African American health care providers in communities across the state.

Relevant quotes:

Referring to statistics on the lower health status of African Americans, one African American respondent said, *“It’s what the government wants you to believe.”*

“It’s what the government wants you to know.”

“They are not going to put out the truth.”

“If someone has an abortion, there is no birth certificate.” The implication being that White women have abortions more frequently than African Americans and this reduces infant mortality rates.

White people are *“ashamed and don’t want to deal with how their family and friends look at them and to let friends and family know that their daughter was having sex at an early age. ... Black mother say to their children ‘if you lay down and get that baby, you are going to have it’.”*

“No study is accurate.”

In a focus group with African American women from an AME church in the Research Triangle, the issues of higher rates of infant mortality and other chronic health problems among African Americans was a central issue of discussion. The women seemed to feel that many African American women take a laissez-faire approach to prenatal care because it was a cultural norm to do so. Young women watched older peers have pregnancies with apparently little medical attention and a casual attitude toward prenatal care. They explained that when some African American women seek prenatal care, it is often too late, perhaps after they have gestational diabetes. This group emphasized that health risks specific to the African American community, particularly stress, impact them dramatically. Racism also plays a role, since blacks do not have access to the same quality of care and may be dismissed by doctors as being noncompliant with care or “too stupid” to take an interest in their own health.

American Indians

Two focus groups comprised entirely of American Indians were convened—one comprised of health educators from the Native American Rural Health Organization (NARHO) representing tribes from across the state and one comprised of Lumbee in Robeson County. It is important to note the virtually all participants in these two focus groups worked in the health care field or were health educators or liaisons in their communities. A few additional American Indians were included in other focus groups.

Women in the Lumbee focus group indicated that elders and family were important sources of health information and advice. The NARHO women, on the other hand, said that the quality of health information they received from their mothers and grandmothers was poor. Both groups indicated that they relied on traditional herbal remedies and traditional healers as part of their normal health care regimens. They not only felt more comfortable with the level of respect they received from these healers, but also had more trust in them for certain problems.

There was a general sense of being disrespected by doctors, particularly in clinics. Doctors sometimes talk down to them or keep them waiting for extended periods of time. This was

particularly problematic during pregnancies, in which they were rotated from doctor to doctor. For many American Indians, being forced to seek medical care “outside of the community” (meaning from a physician who is not American Indian) caused difficulties. Yet, confidentiality was also a concern at clinics within small American Indian communities. A core issue for American Indian respondents was choice in health care and control over the decision-making process.

Among American Indian women respondents, their concerns and experiences with pregnancy were very similar to other women. Two key exceptions were gestational diabetes and post-partum depression. For two of the NARHO women, pregnancy was a turning point regarding their health not only because they had to consider the babies health while *in utero* but also because it was their initiation into the experience of diabetes. After being taught how to modify their diets and check their blood sugar levels they made commitments to themselves not to remain diabetic after delivery. Many of the Lumbee women mentioned that they had experienced post-partum depression. Most of them dealt with it by crying and “praying a lot.” They wanted to know more about the causes and treatment of post-partum depression.

Relevant quotes:

- “I go to the traditional healer because they talk to you and are honest. A lot of times when you see a doctor they talk around you and you’re right there!”*
- ‘Once you get referred to a specialist, that’s when you get talked around and about you.’*
- “There’s a lot doctors don’t know.”*
- “You get treated differently at a private doctor than you do at a health clinic. Especially as a Native American.”*
- “It [how you’re treated by health care providers] has more to do with your social status and how much money you make.”*
- “For American Indians, the community is a strong piece where going outside, there is skepticism.”*
- “Lumberton is the poorest city (county) in the state of NC.”*

Latinas

In the lone focus group with Latinas (who were atypical for Latinas in North Carolina in that they were fluent English speakers and from affluent backgrounds), it was striking what little experience the women had with standard health care services. Five of the seven women said that they do not regularly see a doctor; they only see a doctor if they are “going to die.” When asked about their experiences using health care services, the Latina women were initially very positive, but when questioned about their apparent reluctance to go, they shared many negative stories about doctors’ offices. Most had had the experience of being quickly processed through the appointment and not being understood by the doctors. The most positive experience came from a woman who found a female doctor from Colombia. This doctor took a great deal of time and made the patient feel “very important.”

Relevant quotes:

- “I think the nurses treat you like a case number, not like a person. It’s nasty. You’re in pain and they just don’t care.”*

“Most of the time when I go to see the doctor I feel they are in a rush. They don’t treat me like a human person. I hate it.”

A pronounced difference between the Latinas and other communities surveyed was their reliance on family and community for health information and advice. They turn to their mothers for advice and their mothers turn to their grandmothers. Their families, particularly their mothers, are the gatekeepers of their health. They not only provide information when a problem arises, but they “keep you from doing things that aren’t good for you.” Doctors are not trusted. Money was also a factor in why they do not see health care workers. Having grown up with socialized medicine, their families were not used to the expense of private insurance and care.

Relevant quotes:

“Mothers are the only ones who really listen and know you.”

“When my mother sees I’m really sick, she makes an appointment for me.”

Interestingly, the Latinas initiated the discussion of health by discussing mental and spiritual health. They emphasized the importance of mental and spiritual health to overall health and referred to “high self esteem” and a “healthy mind.” Preventative health was not a concept they really understand or seemed to care about. Health was important, but mostly in what it offers in the here and now (i.e., looking good). Furthermore, they did not mention regular check-ups or medical screenings among healthy behaviors.

Relevant quotes:

“It’s easier to be a healthy man. Women have to care about the home, others, her period. If she knows how to do all of these things, she can be healthy.”

“It’s important for me as a woman to be respected. That’s part of mental health.”

Another significant difference for the Latina group was that immigration was an extremely significant source of stress. When discussing their importance of their families in maintaining their health, the women brought up the significant impact of stress on their health, particularly the stress brought on by immigration. They emphasized the impact of learning and speaking a second language and being misunderstood both verbally and socially. They talked about the “loss of status” that resulted from leaving their home country and moving here, where their parents’ education was not accepted. Growing up, they had found it difficult to make friends outside their immediate cultural community. Many of them continued to find it difficult to make friends outside their cultural community. The women added that the lack of health care providers who speak Spanish provided an additional obstacle to medical care.

Relevant quotes:

“These things [discrimination and prejudices] really affect our health. You feel like no one knows you. That really hurts your mental health.”

“Sometimes you feel like you’re at a low level and you were at a high level in your country. That causes depression.”

For some people, these negative experiences were compounded by their limited health care choices due to their location (e.g., small towns in rural NC), due to Medicaid or private insurance plan, or due to their financial situation.

12. Self-Report Health Status

As part of the research protocol, participants were asked to complete a brief pen-and-paper survey. The survey included some questions about respondents' health and health behaviors. These data are reported in the tables below. Please note that this information is only descriptive as the sample was not random and thus is not representative of the general population.

Table 6. Health Coverage of Subjects

What kind of health insurance or medical coverage do you have?	Total	
	N	% ¹
Private Insurance	94	46.1%
Medicaid	58	28.4%
Medicare	12	5.9%
Does not have insurance	35	17.2%
Other	11	5.4%
No response	3	1.5%

The largest portion of respondents reported that they had private health insurance. Over 28 percent reported that they had Medicaid benefits. Over 17 percent reported that they did not have health insurance or medical coverage.

Table 7. Health Status of Subjects

Would you say that, in general, your health is—	Total	
	N	%
Excellent	26	12.7%
Very good	86	42.2%
Good	69	33.8%
Fair	19	9.3%
Poor	1	0.5%
No response	3	1.5%

The vast majority (76%) of focus group participants described their health as “good” or “very good.” Over 12 percent rated their health as “excellent.”

Table 8. Most Recent Doctor Visit

When was the last time you visited a doctor or health care professional for yourself, whether in a medical office, clinic, or hospital?	Total	
	N	%
Past 30 days	83	40.7%
Past 90 days	45	22.1%
Past 6 months	29	14.2%
Past 12 months	35	17.2%
Past 2 years	4	2.0%
Longer than the past 2 years	4	2.0%
No response	4	2.0%

A very large minority (nearly 41%) reported that they had visited a doctor or health care professional for themselves in the past 30 days. All but 12 respondents (6%) reported having seen a doctor or health care professional in the past 12 months.

¹ Some respondents reported more than one type of coverage so the total exceeds 100%.

Table 9. Vitamin Supplement

In the past seven days, how many times did you take a multivitamin or a prenatal vitamin?	Total	
	N	%
Didn't take	97	47.5%
One to two	30	14.7%
Four to six	17	8.3%
Every day	56	27.5%
No response	4	2.0%

Nearly half of respondents (47.5%) reported that they had not taken a multivitamin or prenatal vitamin in the past seven days.

Conclusions and Recommendations

Knowledge does not change behavior

A primary theme that emerged in all focus groups was that health awareness is not enough to change people's behaviors. Virtually all focus group participants were able to list a wide variety of healthy behaviors. In addition, the key factors to a healthy pregnancy were widely known. While this high level of awareness could be attributed in part to the overrepresentation of health care workers, community health educators, and members of community groups already receiving health services (e.g., Baby Love Plus outreach programs), it is clear that many of the public health messages are being communicated to people. The problem is that knowledge is not enough to change people's behaviors.

Based on these focus groups, a few additional "tipping factors" emerged:

- Knowing family history vis-à-vis chronic diseases (e.g., heart disease, high blood pressure, diabetes, breast cancer, prostate problems)
- Consistent support within the family, including spouses, children, and parents
- Consistent support within community, including community health educators or outreach workers
- Giving people options for health care
- Relationships with health care providers based on trust and mutual respect

Some key issues that people face in managing their health are:

- Managing feelings of depression, particularly as it relates to pregnancy, post-partum, and weight issues
- Stress
- Structure of health care in this country
- People prefer health care approaches that looks at the whole person, including spirituality, in health programs
- Multiple roles of women creating a lack of time for themselves and an increased focus on others

Empowerment

A key factor that emerged over all focus groups was the ways that structural violence, including poverty, lack of education, racism, and sexism among other factors, impacts people's access to health care in general and preventative health care in particular. While lower income and minority focus group members tended to mention economic barriers most frequently, an underlying factor that emerges when looking at the data is self-empowerment. Income or economic status itself was not the determining factor in individuals' sense of empowerment, but rather the linking of various marginalizing characteristics such as low income, low education, unemployment, obesity, or racial or ethnic minority status increased respondents' likelihood of expressing a sense of disempowerment vis-à-vis their lives in general and their health care in particular. Better educated, higher income respondents tended to communicate a sense of self-empowerment vis-à-vis their health. Lower income or minority communities communicated less of a sense of empowerment both in terms of adopting preventative health behaviors, evaluating information about their health, and making decisions about their reproductive health. In focus

groups comprised of people with multiple marginalizing factors (for instance, poverty combined with low levels of educational achievement combined with unemployment combined with racial or ethnic minority status) respondents frequently communicated that they had little or no choice in terms of their health care, living situation, access to food, etc.

For example, while African Americans all experience the very real impact of their minority racial status on their access to health care, poor, uneducated, African American women experience a greater degree of disenfranchisement. In two focus groups comprised primarily of African Americans living in public housing in Durham, NC, the focus group participants perceived that they had very few or no choices vis-à-vis their lives. They did not perceive that they had choice in what they ate, where they lived, where they received medical care, whether they received medical care, etc. Similarly, lower socioeconomic status White women from western North Carolina who were obese expressed a sense of not being in control of their bodies and having limited health care or life choices.

The compounding effect of various marginalizing characteristics on is illustrated by discussion in one focus group comprised entirely of African American women, most from middle class or affluent households and nearly all of whom held advanced degrees. These women emphasized the importance of being proactive in their relationship with health care providers. They discussed the importance of being assertive with doctors and demanding a high level of care. These statements were made in the context of overcoming prejudice (whether active or passive) on the part of healthcare provider. They explained that it helps to find a doctor who listens and speaks with respect and then become informed enough about your body and health issues to ask pertinent questions.

Questions requiring further investigation

This focus group research highlights a number of areas or questions requiring further investigation, either through qualitative or quantitative methods.

Understanding stress

In virtually every focus group, “stress” was mentioned as a significant factor in health and wellness. Yet, how they define “stress” and what causes it is not entirely clear and may well vary between groups or between subpopulations. Additional analysis of the focus group transcripts could yield some more concrete information. Following analysis of the transcripts, additional focus groups specifically discussing stress and its impact on health could be warranted.

Impact of mental health on health

Directly related to the question of “stress” is the impact of mental health on health. Virtually all focus groups included mental, emotional, or spiritual health (sometimes expressed as “feeling balanced” or “feeling good”) as a necessary component of health.

Many focus groups mentioned “laziness” or “lack of motivation” as a significant barrier to healthy behaviors. Additional analysis of the focus group transcripts for this theme is warranted. This analysis should attempt to define what people mean by “laziness” or “lack of motivation.” Could these concepts be an idiomatic expression of depression? What is the relationship

between “laziness,” “lack of motivation,” and “stress”? What is the relationship between “laziness” and the repeated theme of “being overloaded” or lacking time?

Communities warranting additional consideration

This focus group research was remarkable in the representation of a range of voices from African Americans across the state of North Carolina. Given the dramatically higher rates of infant mortality among African Americans, this representation was warranted. Yet, the few focus groups with certain communities in the state raise additional questions.

In two of the focus groups in western North Carolina, the relationship between pregnancy, weight gain, and obesity was a focus of discussion. These focus groups included obese White women with lower socio-economic status. These women described their obesity as major obstacles to healthy behaviors both in terms of its effects on motivation and on prejudice from healthcare providers. One woman described a weight gain of over 150 pounds during her pregnancy. While unique to these groups, these results suggest that weight gain during pregnancy as well as obesity might be important factors in the relationship between women’s health, pregnancy outcomes, and infant mortality. Quantitative analysis of the relationships between pregnancy, weight gain, obesity, pregnancy outcomes, and infant mortality could determine whether additional qualitative research on these issues is warranted.

Due to resource constraints, this project included a single focus group with Latinas. Given the rapid growth of the Latino community in North Carolina, additional qualitative research on issues of women’s health and infant mortality is warranted. Focus groups conducted in Spanish by native speakers using a translated version of this project’s focus group interview guide could yield results that would integrate fully with the results of this study. In addition, review of the available quantitative data on women’s health, pregnancy outcomes, and infant mortality among Latinas in North Carolina could yield additional questions to be addressed in additional qualitative research on these questions in the Latino community.

Finally, additional qualitative research via focus groups and key informant interviews should be conducted based on the results that continue to emerge from the ongoing quantitative analysis of the SIM Collaborative initiative. Given the extremely short time frame for this focus group research project and its timing (i.e., the focus groups were conducted before in-depth quantitative analysis was completed), these focus groups were structured to be exploratory in nature. The additional quantitative analyses called for in the SIM workplan will likely suggest areas where in-depth qualitative research could yield vital information for developing interventions.

Appendix A. Project Timeline

SIMS Focus Group Research Project Timeline

Activity	Start Date	Completion Date
FG Coordinator Hired		Thursday, April 14
SIM Qualitative Research Subcommittee Meeting Raleigh, NC		Tuesday, April 19
FG Facilitator Candidate Interviews		Wednesday, April 27
Focus Group Characteristics	Friday, April 16	Friday, May 6
List of potential convenience groups	Monday, May 2	Friday, May 13
Facilitators schedule Focus Groups	Monday, May 9	Monday, June 13
FG Interview Guide	Monday, May 2	Friday, May 13
Facilitator Training Chapel Hill, NC		Monday, May 16
SIM Qualitative Research Subcommittee Meeting Chapel Hill, NC		Monday, May 16
Focus Groups	Monday, May 16	Thursday, June 23
FG Reports to FG Coordinator	Wednesday, May 18	Monday, June 20
Initial report of preliminary findings		Friday, June 10
SIMS Home Group meeting Greenville, NC		Thursday, June 16
Final Written Report	Friday, June 17	Thursday, June 30



[FIRST STEP Campaign](#)

[Ana María Latino Campaign](#)

[Back To Sleep Campaign – ITS-SIDS Program](#)

[Health Check – NC Health Choice for Children Campaign](#)

Appendix B. SIMS Focus Group Interview Guide

Introduction to Study

Let me begin by thanking you all for being here. My name is _____, and I'll be facilitating our discussion today. My partner, _____, will be taking some notes about the discussion and will keep track of the time. This focus group should take about 2 hours. We are both working with the North Carolina Healthy Start Foundation to conduct focus groups around the state of North Carolina.

In these focus groups we want to learn about people's attitudes, beliefs and feelings about women's health, including things women do to improve their health and the health of their families. We are here to learn from you. You are the experts on this topic. We are here to listen to what you have to say. There are no right or wrong answers to any of these questions, so please just say what is on your mind. You are our teachers for the day.

This focus group is part of a larger, two-year research initiative in North Carolina, known as the State Infant Mortality Collaborative or SIMS. SIMS is comprised of state agency personnel, private organizations, researchers, and academic institutions. We are interviewing approximately 20 groups of 10 people around the entire state about women's health.

Consent

We would like you to sign a consent form, which states that your participation in this discussion is voluntary. [Distribute Consent Forms & Self Report Surveys].

You may refuse to participate in this discussion without any negative consequences. If you choose to participate, you may refuse to answer any of the questions. If at any time you change your mind and want to stop participating, you are free to leave.

We will treat all your responses as confidential, meaning that we will not identify the person (by name or description) who made a particular statement. As we may be discussing some issues that people consider to be private, we ask that everything said here today remains in this room. Researchers involved in this study may publish academic articles about the research results. In any publications resulting from this research, your identity and any identifying characteristics about you will be disguised.

If you have no objections, we will tape record the discussion to make sure we don't miss anything. Afterwards, the tape will be transcribed and all names and identifying information will be removed. You may ask for the recorder to be turned off at any time during the discussion. The tapes will be kept in a confidential file by the NC Healthy Start Foundation. Do you agree to have this discussion taped?

[Turn tape recorder on.]

Rules of Discussion

[Establish with the group what the rules of discussion will be for the day. Explain the process as well as the roles of the facilitator and note-taker.] We want to be respectful of everyone's time so I may need to stop discussion on one topic and move us along to the next. If I need to do that, please do not take it personally. It's just that we have many topics to cover today, and I want to be sure that we discuss all of them.

Personal Introductions

Let's start by going around the room one at a time and introducing ourselves and then we'll start the discussion. When you introduce yourselves, tell us anything you like about yourself, your family, your work, etc. Whatever you'd like to share. [Facilitators make their personal introductions. If you feel comfortable, share some personal information to set the "mood." Remind participants that you are a facilitator and not a health care worker, to allay any feelings they may have about giving "correct" answers.]

[Remember that the questions below are merely suggestions. You do not need to ask each and every question. We need to cover the big topics.]

First, we're going to talk about what "health" means.

1. What do "health" and "healthy" mean?

What does "health" mean to you?

Describe what makes a person "healthy". Describe what makes a woman "healthy."

How important is your health? Is it something you give a lot of thought to or does it tend to fall to the back burner?

What would you tell your mother (daughter, sister or friend) about being healthy or staying healthy?

2. Preventative Health Behaviors

[Definition: smoking cessation, nutrition, vitamins, exercise, sexual behavior & choices, managing stress, male-female relationships, social & kin networks-support, dental care, personal care (beauty, hair, massage, etc.)]

What things should people do to stay healthy? [Make a list on flipchart.] What are some things you know that people should do to stay healthy?

What do you do to keep yourself "healthy"? What do you do to take care of yourself? What makes it possible for you to do these things?

What are some things you know you should do to take care of yourself or to stay healthy, but you don't? [Refer back to list on the flip chart.] What keeps you from doing them? [Probe for external factors like lack of access to health care system, transportation, lack of health insurance, lack of money, etc.]

What are some things your mother or grandmother did to take care of you and help you stay healthy? to take care of themselves? to take care of other family members?

3. Health Information & Advice

Who do you rely on for advice about your health? [Make a list on flipchart.] About your family's health?

How do you like to get information about your health? There are many sources for health information out there- what makes a good source? How can you tell it's trustworthy? [Probe: Dr. recommendation, magazines, websites, news/talk shows, friends and family, etc.]

How do you make decisions about your health?

4. Preventative Health Care Services

[Definition: primary care, community clinics, ER, dental care, OB/GYN, health screenings (including pap smears, mammograms, STDs, bone density exams, cholesterol, blood pressure), traditional healers, traditional medicine or home remedies, religious or spiritual healing (laying on of hands, prayer, meditation, etc.)]

Where do you get your health care? [Make a list on flipchart. Probes: community clinic, doctor's office, family or friends, work, ER, etc.]

When do you go to the clinic/doctor? What makes you go to the clinic/doctor? [Probe: ask about "well" visits]

What things prevent you from going to a doctor? [Probes: money, transportation, fear, communication problems, lack of respect from doctor, nurses, or staff, judgmental attitudes of doctor, nurses, or staff, family members, domestic violence, etc.]

Describe a positive experience with a health care professional, like a doctor, nurse, lab technician, or health advisor. Negative experience.

If you could change something about your experiences with health care professionals, what would it be? When you go to the doctor/clinic, do you feel comfortable asking questions? How well do you understand what the doctor/nurse says about your health or about the treatment?

5. Family, Friends and Relationships

How do your relationships with family members influence your decisions about your health? About your children's health? About your husband's/boyfriend's/partner's health?[Probe: domestic violence]

[Relationships with husbands/fathers of children identified as a hot button issue by many African American women in Kaaren Haldeman's research. Need to think about how we'll handle this in focus groups.]

6. Pregnancy and Reproductive Health

Now, we're going to talk a little about the experience of pregnancy and health.

What is a "healthy pregnancy"? What does that mean? A "healthy childbirth"? A "healthy family"?

What kinds of things should a woman do to have a healthy pregnancy? [Make a list on flipchart. Probes: Before getting pregnant? During pregnancy?]

[For women who have been pregnant:] What did you do when you were pregnant to take care of yourself? To stay healthy? What things did you know that you should do while you were pregnant, but you didn't or couldn't? Why didn't you do them? [Probe for external factors, e.g., work, economic situation.]

What things did you do during your pregnancy that you knew you shouldn't do, but you did? [not sure we can ask this question]

When you were pregnant, who/what did you rely on for information about health decisions? What/who did you trust?

Did pregnancy make you think differently about your health? How?

What kinds of things were stressful during your pregnancy? [Probes: feeling tired, feeling sick, work, school, being pregnant without having planned it, taking care of other children, relationship with husband or father of fetus, domestic violence or abuse] How did you handle this stress? What things did you do to relieve stress?

7. Health Disparities

[For this area, we will need to tailor some questions to each specific group. One possibility is to present some information about health disparities (and particularly IM data) for the community where the group is located.]

Appendix C. List of Focus Group Characteristics for Recruitment

Ideal Focus Group Characteristics

Group #	Characteristics	Priority
Specific Guidelines		
1	Native Americans / American Indians → Representatives of eight tribes of North Carolina	High
2	Robeson County: Native Americans / American Indians	High
3	Robeson County: African Americans	High
4	Robeson County: European Americans	High
5	Mecklenberg County: → African American (Urban) Women → County with high # of "excess infant deaths"	High
6	Mecklenberg County: → African American (Urban) Male Companions of Women	
7	African American (Rural) - Warren County - Northampton County - Hertford County - Anson County → These counties are 41.3-62.3 % African American → Infant Mortality Rate > 15 (1999-2003)	High
8	Latino (English speaking) - Greensboro - Research Triangle - Wake County - Chatham County - Lee County	High
Some Additional Guidelines		
9	Women ages 18-25 years	
10	Women ages 25-37 years	
11	Women ages 38+	
12	Mothers	
13	1 st Pregnancy	
14	Male companions of Pregnant Women	
15	Women who have experience Preterm Delivery or Very Low Birth Weight	
16	Community leaders/opinion makers/traditional healers/elders	Low
17	Women without private health insurance or Medicaid	High
18	County with Infant Mortality Rate < 7 (1999-2003) - Haywood - Henderson - Watauga - Wilkes - Yadkin - Alexander - Stokes - Union - Orange - Chatham - Lee - Wake - Granville - Brunswick - New Hanover	High
19	Cumberland County → Great disparity in Infant Mortality Rates between European Americans and other racial or ethnic minorities → County with high # of "excess infant deaths" → Fort Bragg	
20	County with "excess infant deaths" - Guilford - Forsyth - Wake - Robeson - Pitt - Gaston - Onslow - Alamance - Buncombe - Durham	

Facilitators: _____

Date: _____

Location/Site: _____

Appendix D. List of Focus Groups

Group #	Date	Group (Meeting Location)	Facilitators	Characteristics
1	May 16	Statewide Group (Chapel Hill, NC)	All	Educated women of diverse racial and ethnic backgrounds
2	May 31	Martin County	Butler-Hill & Bunch	Church group. Women ages 26 to 68 with diverse racial/ethnic backgrounds and diverse educational backgrounds
3	June 1	Stroller Club (Asheville, NC)	Guciardo & Crowe	New mothers found through Women's Resources Center at the hospital
4	June 2	Mecklenburg County (Charlotte, NC)	Guciardo & Jones	Lower socio-economic status women from diverse racial & ethnic backgrounds
5	June 8	Fayetteville Place (Durham, NC)	Hall & Crowe	Grandmothers & other caregivers
6	June 9	MacDougle Terrace (Durham NC)	Hall & Crowe	Mothers aged 18 years and older who receive visits from Durham County Health Dept & BabyLove Program, lower income
7	June 9	Buncombe County ()	Guciardo & Jones	Mothers of children in early Head Start program, lower income, rural families
8	June 9	UNC (Chapel Hill, NC)	Hall & Crowe	Women with advanced educations
9	June 10	Haywood County	Guciardo & Jones	predominantly White community with low Infant Mortality Rate
10	June 14	Hertford County	Butler-Hill & Bunch	Rural, primarily African American communities with Infant Mortality Rate greater than 15
11	June 14	Forsyth County (Winston-Salem, NC)	Jones & Crowe	Fathers parenting group
12	June 15	Warren County	Bunch & Butler-Hill	African American women
13	June 17	Pitt County	Bunch & Butler-Hill	African American women
14	June 17	Statewide Group (Raleigh, NC)	Jones & Guciardo	Native American / American Indian women; Native American Rural Health Organization (NARHO) health educators
15	June 17	AME Church (Carrboro, NC)	Jones & Guciardo	African American women
16	June 18	NCCU students (Durham, NC)	Jones & Butler-Hill	African American women, primarily in their 20s
17	June 18	Project Direct (Raleigh, NC)	Jones & Butler-Hill	African American Women ages 18-50
18	June 16	Robeson County	Jones & Note taker	Lumbee Indians
19	June 16	Robeson County	Jones & Note taker	African Americans
20	June 23	Latinas (Cary, NC)	Jones & Guciardo	English speaking Latinas
21	June 13	Tyrrell County	Bunch & Butler-Hill	African American women, rural eastern NC, the poorest county in NC

Facilitators: _____

Date: _____

Location/Site: _____

Appendix E. Self-Report Survey

Survey & Demographic Information

1. What kind of health insurance or medical coverage do you have?
 - Private insurance
 - Medicaid
 - Medicare
 - I do not have health insurance or medical coverage
 - Other (If other, describe) _____
 2. In the past seven days, how many times did you take a multivitamin or prenatal vitamin?
 - I didn't take a multivitamin or a prenatal vitamin.
 - 1 to 3 times
 - 4 to 6 times
 - Every day
 3. Would you say that, in general, your health is—
 - Excellent
 - Very good
 - Good
 - Fair
 - Poor
 4. When was the last time you visited a doctor or health care professional for yourself, whether in a medical office, clinic, or hospital?
 - Past 30 days
 - Past 90 days
 - Past 6 months
 - Past 12 months
 - Past 2 years
 - Longer ago than the past 2 years
 5. a.) Do you have any children?
 - No → Go to Question #6
 - Yes.
 - b.) What are your children's ages?
 6. What year were you born? _____
 7. What is your sex?
 - Male
 - Female
 8. Which of the following best describes your relationship status? (Select only one.)
 - Single
 - Living with significant other, not married
 - Married
 - Separated
 - Divorced
 - Widowed
 9. What is your highest level of education?
 - Some high school
 - High school diploma or GED
 - Some university
 - Associate's degree
 - Bachelor's degree
 - Master's degree
 - Ph.D. degree
 10. What is your occupation?

 11. What is your annual **household** income?
 - Less than \$15,000
 - \$15,000-\$29,000
 - \$30,000-45,000
 - \$45,000-\$60,000
 - Over \$60,000
-

12. How would you identify your race? (You may select more than one.)
- American Indian or Native Alaskan
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White

13. How would you identify your ethnicity? (Select only one.)
- Hispanic or Latino
 - Not Hispanic or Latino

14. What is the postal zip code at your home?

Men do not need to respond to the following questions.

15. When was the last time you had a gynecological check-up and pap smear?
- Past 6 months
 - Past 12 months
 - Past 2 years
 - Longer ago than the past 2 years

16. Have you ever been pregnant?
- No → Thank you! You've completed the survey.
 - Yes. → Go to Question #16

17. How many times have you been pregnant?

18. How many live babies have you given birth to?

19. a.) Have you ever had a stillbirth (baby born dead near full-term), miscarriage, or abortion?
- No
 - Yes. If "yes," check all that apply.
 - b.) Stillbirth
 - Miscarriage
 - Abortion

20. Have you ever had a premature birth (baby born more than 3 weeks before your due date)?
- No
 - Yes

21. Have you ever had a low birth weight baby (baby weighed less than 5lbs. 8oz. or 2.5 kilograms at birth)?
- No
 - Yes

22. Have you ever had a baby die during its first year of life?
- No
 - Yes

23. Are you currently pregnant?
- No
 - Yes

Thank you for completing this survey and for participating in this focus group. Your responses will help us to improve the health of women, babies and families in North Carolina.



[FIRST STEP Campaign](#)

[Ana María Latino Campaign](#)

[Back To Sleep Campaign – ITS-SIDS Program](#)

[Health Check - NC Health Choice for Children Campaign](#)

Appendix F. Informed Consent Document

Consent to Participate in a Focus Group on Women’s Health

What is the purpose of this focus group?

The purpose of the focus group is to learn about attitudes, beliefs and feelings about women’s health, including things women do to improve their health and the health of their families. This information will be used by the North Carolina Healthy Start Foundation to improve their public education campaigns. The information will also be used by researchers and the State Infant Mortality Collaborative to learn more about the relationship between women’s health and having a healthy baby.

Why have you been asked to take part?

You have been asked to be in this study because you belong to a community group, which was chosen by the focus group planners, or because you expressed interest in participating.

What will you be asked to do?

You are being asked to participate in one focus group discussion that will take about 2 hours of your time. We will ask you about your beliefs and feelings about women’s health and behaviors. Your ideas and opinions are important to us, so please just say what’s on your mind. There are no right or wrong answers to any of the questions we are asking.

What are the benefits of participating?

We do not promise you any direct benefit from participating. The focus group, however, may allow you to explore your feelings and beliefs about health and what it means to be healthy. Other people may benefit in the future because, the information from this focus group may increase our understanding of the best ways to talk to people about health issues.

Are there any risks?

No. There are no known risks from participating in the focus group.

Are there any costs?

No. There is no cost to participate.

Will you receive any compensation?

Yes. You will receive a \$25 gift card to thank you for participating.

Right to Refuse or Withdraw from the Focus Group

Participation in this focus group is voluntary. You have the right to withdraw your consent or stop participating at any time without penalty.

Confidentiality:

If you agree to participate in this focus group, please understand that your participation is voluntary. All the information you provide will be kept confidential. The only exception is if you express the intent to harm yourself or others. This signed consent form and your name will be kept separate from the focus group information. You do not need to tell us your name and you may use a fake name if you wish. Audio-taping is preferred for all focus groups, however, you may ask to stop the tape recording at anytime. All tapes will be transcribed (typed up) without names or other identifying information to protect your confidentiality. Every effort will be taken to protect the identity of the participants in the focus group. However, there is no guarantee that the information cannot be obtained by legal process or court order. You will not be identified in any report or publication of this focus group or its results.

Who can I contact to answer questions about the Focus Group?

If you have questions about this focus group, you may call Dr. Jennie E. Burnet, SIMS Focus Group Coordinator, at 919-256-3598 or Ms. Janice Freedman, Executive Director of the North Carolina Healthy Start Foundation at 919-828-1819.

Participant’s Agreement

I have read the information provided above and voluntarily agree to participate in this focus group. If I have any questions or concerns that arise in connection with my participation in this Focus Group, I should contact Dr. Jennie E. Burnet, SIMS Focus Group Coordinator, at 919-256-3598 or Ms. Janice Freedman, Executive Director of the North Carolina Healthy Start Foundation, at 919-828-1819. I understand that I will be given a copy of this consent form.

Name of Focus Group Participant (Print)

Signature of Focus Group Participant

Date

Name of Person Administering Informed Consent (Print)

Signature of Person Administering Informed Consent

Date