



**Oklahoma Preconception and Pregnancy Health
Focus Groups
Summary Report and Recommendations**



**Preparing
for a
Lifetime**
It's Everyone's Responsibility

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1. BACKGROUND AND PURPOSE OF STUDY

Infant health is an issue of particular concern in Oklahoma. The infant mortality rate, defined as the number of deaths to infants less than 1 year of age per 1,000 live births, is an important indicator of health in Oklahoma and the nation. It is associated with a number of factors such as maternal health, quality and access to medical care, socioeconomic conditions, and public health practices, all of which were addressed through focus group questions.

Oklahoma's infant mortality rate (IMR) has consistently remained above the national rate since 1992. While some improvements have been observed, the state's IMR of 8.5 deaths per 1,000 live births for 2007 is far greater than the national IMR of 6.7. The 2007 African American/Black IMR is more than twice the rate of white deaths, and little has changed for decades. The American Indian IMR is also higher than white infants.

In response, the Oklahoma State Department of Health (OSDH) Commissioner's Action Team on the Reduction of Infant Mortality was convened May, 2007, with the overarching goal of reducing infant mortality in Oklahoma. The team has expanded to include external partners in a statewide collaborative to reduce infant mortality, other adverse birth outcomes, and to reduce racial disparities for such outcomes. The initiative is entitled "Preparing for a Lifetime, It's Everyone's Responsibility." One workgroup in this initiative is the "Preconception/Interconception Care and Education" Workgroup. This workgroup was charged with learning more about how women perceive health and pregnancy before, during, and after pregnancy in order to impact maternal and infant health outcomes in Oklahoma.

Focus groups were conducted in the Fall 2009, Spring 2010, and Summer 2010 to assess what women know, need to know, and how they learn about pregnancy health during their reproductive years. The information gathered in these focus groups will help Oklahoma State Department of Health (OSDH) programs and partner agencies understand how to provide services and interventions in culturally appropriate ways. The OSDH and partners collect quantitative data using a variety of tools targeting women of reproductive age; however, qualitative information, such as how and why the statistics report what they do, is largely left unanswered.

The focus group elicited a discussion of health before, during, and after pregnancy for women in Oklahoma. The focus groups oversampled African American/Black women because the disparities for this population are the greatest. Women were encouraged to discuss how they view health, health care in their community, how their relationships impact their health, and pregnancy and infant health. Specific discussion areas included: individual health, preventive health behaviors, health information and advice, relationships, pregnancy and reproductive health, and infant health and care.

2. DEVELOPMENT OF THE FOCUS GROUP QUESTIONNAIRE

Questions for the focus group tool were largely based on the work of the [North Carolina State Infant Mortality Collaborative](#) and were used with permission from authors of the focus group report. After several telephone and email communications with the designers and facilitators of the North Carolina tool the Preconception/Interconception Workgroup modified and created new questions based on Oklahoma's needs for information on women of reproductive age.

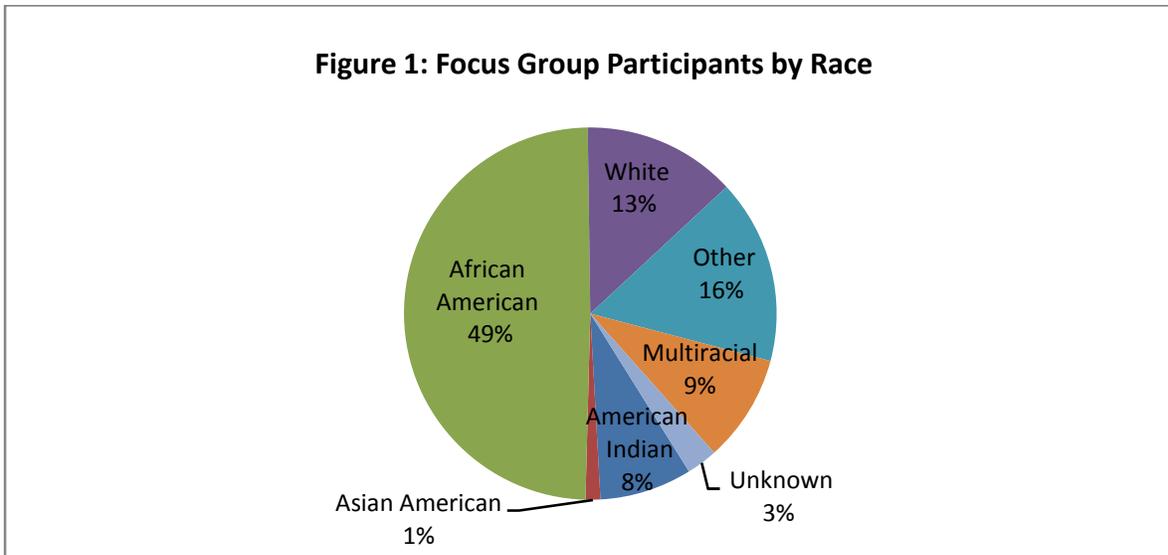
Members of the workgroup were trained in focus group facilitation and note taking (see Appendix D). Facilitators were members of the Preconception/Interconception Workgroup and/or partners of the initiative. All focus groups had a trained facilitator and note taker. Some groups had two note takers. Participants self-selected to participate in the focus groups, some knew the facilitators prior to participating, and some did not. Notes from the focus groups were transcribed and organized in an Excel worksheet. Survey data were entered into an Excel spreadsheet and analyzed using Excel.

3. RECRUITMENT AND DESCRIPTION OF PARTICIPANTS

Thirteen focus groups were conducted with a convenience sample of a variety of women at different stages of the reproductive health life cycle (non-parents, parents, and a few grandparents). The majority of the groups were specific to both pregnancy experience (none or one or more) and race or ethnicity. One Spanish speaking group was facilitated, three groups with white women, two groups with American Indian women, and six groups with African American/Black women were also brought together. One group consisted of adolescent mothers. Groups were facilitated in the two major metropolitan areas of Oklahoma: Oklahoma City and Tulsa. Overall, 75 women participated in these focus groups.

Women were given a tote bag with various items (notepads, books, magnets, music CDs) inside as an incentive to participate. The groups generally took about two hours and were held with women already assembled in a group (women's groups at churches, play groups, student groups, health clinics, etc.). From these focused discussions a synopsis was written detailing some of the issues faced, barriers to care, and education about health issues as perceived by these women in our state.

Figure 1: Focus Group Participants by Race



Women in the groups were asked to fill out a short survey upon entering the room (see Appendix A). The survey asked general demographic questions and a few health and reproductive history questions. From the survey, information was gathered about the composition of the focus groups in terms of average age of the participant, racial identity of the majority of participants in each group, and parenting status. Forty-nine percent of focus group participants were African American/Black. Approximately 13% were white; 8.0% were American Indian, 9.0% were multiracial, and 16.0% were “Other” which was written in primarily as Hispanic (see Figure 1). Twenty-one percent of participants were ethnically Hispanic. Fifteen percent of participants were under the age of 20, 18.6% were between the ages of 20-24, and 36.0% were 30 years old or older. More than half of the women in the focus groups (52.5%) had at least some college education, 31.4% had a high school education, and 18.4% had less than a high school education. More than one in four were married (29.4%). Approximately half of the women in the groups reported annual incomes of \$15,000 or less. Twenty-seven percent used Medicaid/SoonerCare and 13.3% were uninsured (see Table 1).

Table 1: Demographic Profile of Focus Group Participants	
	%
Maternal Ethnicity	
Hispanic	21.3
Non-Hispanic	69.3
Unknown	9.3
Maternal Age	
<20	14.6
20-24	18.6
25-29	24.0
30+	36.0
Unknown	6.7
Maternal Education	
<12 years	18.4
12 years	31.4
>12 years	52.5
Marital Status	
Married	29.4
Unmarried	70.6
Annual Income	
< \$15,000	49.3
\$15-29,000	20.0
\$30-45,000	13.3
> \$45,000	18.5
Insurance Status	
Medicaid/SoonerCare	26.7
IHS (only)	2.7
Private	34.7
None	13.3
Other	21.3

Among the groups of women, 14.7% of women had never been pregnant (see Table 2). Of those who had been pregnant, 31.7% experienced a stillbirth, abortion, or miscarriage. Twenty-eight

percent of women had been pregnant one time, and 12.0% had four or more pregnancies. Twenty-three percent were pregnant at the time of the focus group and 29.3% of women had no children. Almost 30% had at least one child under the age of one (data not shown).

Table 2: Health History of Focus Group Participants	
	%
Vitamin Consumption	
None	42.7
Everyday	28.0
Some (1-6 times per week)	29.4
Current Health Rating	
Excellent	18.6
Very Good	25.3
Good	41.3
Fair/Poor	14.6
Last Doctor Visit	
≤ 30 days	45.3
≤ 90 days	25.3
6-12 mos.	18.6
> 12 mos.	10.7
Currently Pregnant	
Yes	22.7
Unknown	8.0
No	69.3
Pregnancy History	
0	14.7
1	28.0
2-3	37.3
4+	12.0
Unknown	5.3
Stillbirth, Miscarriage, Abortion	
Yes (among women with pregnancy histories)	31.7
Have Children	
No	29.3
Yes	69.3
Unknown	1.4

4. SUMMARY OF TOPICS AND FINDINGS

WHAT DOES HEALTHY MEAN:

What does health mean to you?

Most groups had similar ideas of what healthy meant to them. Many groups talked about being healthy in multiple areas, physical, mental, emotional, some even mentioned the idea of being “spiritually healthy.” The idea of taking care of one’s self in order to be healthy was dominant among groups, and that being healthy meant not being sick. One focus group member spoke about being “well-balanced.” The idea of leading an active life and/or “being in shape” also struck many groups as an important part of health. One focus group member stated “health is the key of life.”

What would you tell someone else about being healthy or staying healthy?

Health advice varied among the groups. However, there were a few pieces of advice that groups agreed upon. Consensus from across several groups included: stop (or do not start) smoking, exercise, eat right, and the overall importance of becoming or staying healthy. One group was very focused on mental health and making sure people knew about the importance of mental health on overall health. Other pieces of advice offered by various groups included vaccinations, getting enough sleep, seeing your doctor or health care provider regularly (although in another section the groups will differ on what that really means), “nothing in excess,” and having good overall hygiene.

PREVENTIVE HEALTH BEHAVIORS:

What things do you know you should do to stay healthy?

The overwhelming majority of groups stated that eating right and exercise (or working out) were on their lists of things you know you should do for health. But as one group member put it, these are often “things we know we should do but don’t do.” Another common response among groups was a regular doctor visit. Several groups agreed that dental health was important and going to the dentist is something you should do, as well as brushing your teeth. A few groups mentioned reducing or eliminating stressors, drinking water, and staying positive. Other items mentioned by at least two groups were getting enough sleep, refraining from smoking, taking care of one’s self, and taking vitamins. Some focus group members also mentioned washing your hands, taking prescription medicines, being well informed about health information (and understanding what is a fad and what is fact), and abstaining from drugs and alcohol. One group

felt that it was important to “keep your mind right” and to “take care of your thoughts to control them internally.”

What are some things you know you should do to stay healthy but you don't?

A similar consensus was found in things you should do but don't, for example, women responded that they should avoid second hand smoke, exercise, eat healthy foods, avoid fried/unhealthy foods and get enough sleep but that there were barriers to this. As one member of a focus group with women with children stated “right now, it's hard.”

What would motivate you to practice some of those healthier behaviors?

Time constraints, lack of money or health insurance, and outside stressors were barriers for all women, both with and without children. Having someone to exercise with or having a family member or friend diet with you seemed to be positive motivators for physical activity and healthier eating. For some women, the idea of gaining one more pound, or beginning to look unhealthy were motivators towards practicing some healthier behaviors. For women with children, being an example for their children was an important motivator, but again the issue of the cost of healthy living, no day care, no money for gym memberships, little or no free time, and a lack of transportation kept some women from adopting healthier behaviors.

What keeps you from doing those things to stay healthy?

Time, motivation, money, and child-rearing responsibilities were popular answers to this question. One group listed fear and denial as contributors to this. Another simply said “lazy” and “can do it, just don't want to do it.” Certainly a combination of internal and external motivators exists for women, both with and without children, many of them similar. One group also mentioned the lack of sidewalks in some areas and neighborhoods that keep people from practicing healthier behaviors, like walking.

What advice did your mother or grandmother give you about staying healthy?

For many of the women in all of the focus groups, eating healthy, including consuming vegetables and fruit was a message passed down from their mother or grandmother. One woman stated she was told to always fix a meat and two vegetables for dinner. One participant said her parents said “don't end up like me” and to take care of herself, do things to avoid heart disease and other health problems. Other advice from mothers and grandmothers included drinking water, drinking milk, taking care of your body, and practicing safe sex. Another group discussed the unhealthy behaviors they learned from their grandmothers, like cheating on medically prescribed diets (for diabetes) and another group agreed “it was very hard to be in that environment.”

HEALTH INFORMATION AND ADVICE:

Who do you rely on for advice about your health?

In several groups, many women indicated that they look to their husband or significant other for advice or information about health or health care. Most groups also mentioned a doctor or nurse they knew personally (as their provider or as their friend), their mom or grandma, other family, friends, and internet resources as sources for health information. One participant stated they were more likely to talk to family first because they were “afraid the doctor doesn’t really listen.” Another participant stated that she likes to receive health information from her children, when they bring it home from school.

How do you like to get information about your health? How can you tell if it’s trustworthy?

Internet research was dominant in this category for all groups of women. The groups differed on how much they trusted the information they received from television. Some women perceived that information was trustworthy if it was presented on the news or if it came from government sources; other women felt that no information was trustworthy if it was presented on TV. Many felt their doctors were trustworthy, but a few groups mentioned double-checking information received from medical professionals with either someone else who had experienced their health issue, another health care provider they knew personally, or the internet. For Spanish speaking women, information provided in their own language felt trustworthy and was most helpful.

If you go to websites or read health brochures and magazines, what about them attracts and keeps your attention?

Most groups agreed they only want to pick up materials that have short, condensed information. They preferred to visit websites for topics they had an interest in or needed. Many of the descriptors for attracting and keeping attention were similar for all the groups: catchy (or informative) titles, interesting pictures (including those with “cute boys” for the younger females), relevant information to their needs and lifestyles, eye-catching design, and easy to read information and statistics. One woman mentioned that she preferred brochures and websites that advertised preventive measures, “like, do this to keep from getting that.”

PREVENTIVE HEALTH CARE SERVICES:

Where do you get your health care?

Many women were very specific in their responses to where they received their health care. Most received their health care from a private doctor or a community health clinic. Several

groups mentioned the Emergency Room (ER) as a provider of last resort for health care. One woman stated it was “nowhere if I am lucky, if unlucky-ER.” Across and within the individual groups, those without health insurance had differing levels of access to health care in their communities.

How often/when should people go to the doctor?

Although all the groups felt it was important to go to the doctor for regular checkups and sick care, there was not an overall consensus of how frequent the checkups should be for women. Some stated every few months, others felt that every six months was appropriate, and others felt an annual checkup, if otherwise healthy, was all that was necessary. There were women who stated they needed to feel bad for several days or weeks before they would go for sick care. Women in one group reported they did not trust doctors because “they give you medicines that don’t make sense” meaning that the doctors did not provide an explanation as to why the patient should take that particular medication.

What makes you go to the clinic/doctor?

Feeling sick or being in pain makes women go to the doctor or clinic. As one stated, “if not able to live my life and function, then I go.” A few also mentioned annual exams, birth control, immunizations, and child health visits as reasons for visits to the clinic/doctor. For one group, the reasons mentioned were primarily external: having to get better to care for others, “to keep your kids from getting sick,” or to avoid missing work for fear of job loss.

What things prevent you from going to a doctor?

The two most common responses across the groups were cost and fear. Not having enough money or insurance to cover necessary care was a barrier for many women. Different phobias and fears, from general to specific were also discussed. Several indicated being afraid to find out what might really be wrong. One woman said she did not like needles. For some women it was procrastination or even the thought that they “will be/feel better tomorrow.” The need for child care and the issue of not wanting to take their children to a place where sick people might be was brought up by several participants that were mothers. Other barriers mentioned included the time it takes to be at the doctor, not having transportation, not being able to take off from work, embarrassment about symptoms, the process of getting necessary paperwork (referrals), and “not [being] aware you really need to go (that there is a problem).”

Describe a positive experience with a health care professional, like a doctor, nurse, lab technician, etc.

Overwhelmingly the issues of customer service, being treated courteously, experiencing care and compassion from providers, and feeling like the doctor or provider was listening were described in the positive encounters women had with health professionals. The younger mothers had more

difficulties describing a positive response than the other groups of women. Attentive and friendly providers and staff helped create a positive experience for these women. Participants also commented on the advice they received; they preferred visits where providers were “informative instead of vague” and would “explain to you what and how [the problem] can affect you.” Other positive experiences included having a consistent experience with the same health care provider every time she was seen (medical home), seeing staff wash their hands and follow hygiene protocol, having staff go out of their way to make follow-up appointments or translate documents, and being able to call their physician directly when they needed care.

Describe a negative experience with a health professional.

Conversely, negative experiences were much easier for all of the groups to describe. Like positive experiences with health care providers, negative experiences largely fell under the topic of customer service. Poor customer service, such as not being treated politely, not being listened to, having concerns go unnoticed or dismissed, staff ignoring clients and attending to their own personal business were all listed by multiple women across all the groups. One woman stated she “had to get a referral from my doctor but the group sent my referral to some other place. Took [me] out of it and never considered what was best for me.” Several women reported misdiagnoses for themselves or a child and the stress and complications that caused, many without apologies or concern from the provider. One woman stated her prenatal care provider tried to coerce her into giving her baby up for adoption and to sign legal papers that were not translated for her. Other negative experiences included long wait times before and during appointments, doctors having poor bedside manner, doctors appearing to be rushed and in a hurry, seeing clients in a non-private setting, chart mix-ups, and doing procedures (like breaking their water) without explanation or permission. There were a few who had no negative experiences and did not report on this question, but they were in the minority.

How well do you understand what the doctor/nurse says about your health or treatment?

All of the groups agreed they understand their doctor/nurse or if they do not understand, they ask follow-up questions. Some women stated they ask the doctor to rephrase what they said to ensure they understand the information, as one woman put it: “I make them break it down if I don’t get it.” Some women stated they sometimes call the office back if they don’t remember or still don’t understand once they get home. The Spanish speaking women indicated they have learned the importance of having translators with them and they agree that having written materials in Spanish is also helpful. One woman remarked “[it] sometimes doesn’t seem like *they* understand.”

When you go to the doctor/clinic, do you feel comfortable asking questions? Why or why not?

Almost all women in the groups indicated they were comfortable asking questions. As one woman said “this is your life and it isn’t something you play with - a life is very valuable.” One woman who responded no said it was due to confidentiality issues because “too many people I know work in the clinic - nosy.” Other women who said sometimes they were uncomfortable said it was because they felt intimidated or felt like the provider wasn’t listening. Overall the consequences of not understanding and not knowing what might be wrong were felt to be too great to not ask questions or call the clinic back for more follow-up if they didn’t understand when they got home.

If you could change something about your experiences with health care professionals, what would it be?

Reductions in long wait times once the women arrived at their appointments, customer service, and cost were the most mentioned aspects that would improve their experiences with a health care professional. Some women felt their insurance type created changes in their treatment and wanted to be treated well without respect to payment type. Feeling rushed through an appointment and wanting “more say so in my health care” were also interactions women wished they could change. In several groups women stated that their providers don’t listen to them, don’t spend enough time with them, and create an “assembly line feeling.” The issue of no continuity of care (no medical home) also came up in one group of low income mothers, which was frustrating to them and contributed to their feelings of not being listened to and not being respected. There were some women across several groups who said “nothing.”

FAMILY, FRIENDS, AND RELATIONSHIPS:

How do your relationships influence or affect your health?

The majority of the groups discussed the negative impact family, friends, and other relationships have on your health. A few groups and some individual women in more negative groups were positive about the impact of relationships on their health or mentioned positive examples, as well as, negative. However, the overwhelming response to this question was negative. Stress was high on the list of ways relationships impact health, as one woman said it can “take a toll on health.” Some women indicated their relationships caused or exacerbated hypertension, depression, irritability, drinking, and/or overeating (or binge eating). Domestic violence was mentioned in some groups as part of a relationship that negatively impacts your health; one woman said “a stressful relationship made my chest hurt.” Among those positive responses to the question, women mentioned family or spousal support to stay healthy or fit, motivation that

can come from a supportive relationship to “care for your health,” and that if your relationships are “good” then “it reflects good on my health.”

How would you describe a “healthy family?”

Some groups were more cynical than others, the response “is there one” or “not one family is healthy” came across in several different groups. Some groups focused on physical health primarily, such as exercising together, taking vitamins, and not being sick, but many groups mentioned good communication, support, eating meals together, working together to solve problems or achieve goals, financial security, and faith as important components of healthy families. One respondent without children said a healthy family is one “where children are not bearing the responsibility of their parent’s failure.” One group of inner-city young mothers was perhaps the most jaded about healthy families defining them, as one member stated, “people that are dependent and supportive of each other, but there isn’t one out there.” Several in that group felt betrayed or abandoned by members of their family either during or after their pregnancy. Only the Spanish-speaking mothers mentioned love.

Have you or anyone in your family used alternative or herbal medications? If yes, what were they and what were they used for?

Several American Indian women reported using traditional healers or medicine men, for “maintenance, wellness, balance in your mind and emotions.” A variety of home remedies were mentioned by other participants. Some did not have any, some were not sure what that meant, and others were not specific. The remedies were recorded as they were suggested and some do not have Federal Drug Administration (FDA) recommended uses. Home remedies in the various groups include: chamomile tea for stomach, valerian root to sleep better, kidney beans for kidneys, thyme leaves w/hot lemon, marijuana, hot towels for cramps, mustard on a burn, hot salt water for canker sores, Kani as an immunization booster, St. John’s Wort for depression, fish oil/flax seed, B12, peppermint tea with lemon and honey for stomach pain, took supplement for lactating, DHEA for lupus/fibromyalgia, castor oil, baked potatoes, chicken soup, Vicks on kids feet and putting socks on them, olive oil/vegetable oil, aloe vera, herbs and spices (oregano, cinnamon, onion, garlic, honey, put in food processor), Melatonin, Noni juice (commercial drink), Lavive juice, cod liver oil, vinegar, garlic, Karo syrup, flour (browned and made into a paste), honey, rum, frozen carrots/apples. (These are reported for informational purposes only and are not endorsed by the “Preparing for a Lifetime” initiative; all remedies are reported as they were recorded.)

PREGNANCY AND REPRODUCTIVE HEALTH:

What does the term “healthy pregnancy” mean to you?

Among the groups without children (and non-pregnant) responses to this question ranged from “how the baby turns out,” mother and baby being healthy, going to [prenatal] appointments regularly, having no complications, eating healthy, staying stress-free, being educated about what to expect, having a full-term baby, gaining weight, not using substances (alcohol and other drugs), and having safe sex - even while pregnant. A couple of women in these groups were unsure about what the term “healthy pregnancy” meant. One woman said a healthy pregnancy “starts before you get pregnant.”

Women who were already pregnant or had already had at least one baby stated that a healthy pregnancy included: going to nine months gestation, having a baby that weighed seven pounds or more, taking prenatal vitamins, going to prenatal care, eating right, drinking water, having a proper or healthy weight for mom and baby, getting adequate rest and exercise, “just doing good,” not being on bed-rest, “having a normal pregnancy,” no complications and being able to stay active throughout the pregnancy. One younger mom remarked “knowing you’re pregnant when you get pregnant” and another said “when you know [you are pregnant], taking vitamins and doing what you’re supposed to do.”

Some groups were very clear on the importance of prenatal care and vitamin use during pregnancy. And almost all the groups felt that a healthy pregnancy led to a healthy mom and baby. Women overall seemed to know what things they could do to help their pregnancy be healthy and what things to avoid.

What kinds of things should a woman do before getting pregnant to have a healthy pregnancy?

Both women with and without children were asked this question. Those with no children (and non-pregnant) stated across the groups that women should: stop smoking or using other substances, take folic acid or a multivitamin, be well-balanced and stable – mentally, financially, physically, spiritually, and “be sure you know who you’re having sex with” so that you “pick a good father.” Other suggestions mentioned were getting your well-woman checkups, keep taking your birth control pills, eat “good,” exercise, get counseling for at least 6 months, “make sure [you] have realistic expectations of motherhood,” decide when and if she wants to get pregnant, and lastly, “know that you can do it by yourself if you have to” if you do become pregnant.

Groups with mothers had similar advice for preparing for pregnancy: take vitamins (folic acid), eat healthy, stop smoking and drinking, get a check up with a physician, plan with father/spouse about children/pregnancy, don’t “be lazy,” consider finances, employment, options, etc. One

woman said “when not expecting to get pregnant, [these things] can be difficult.” Across almost all of the maternal groups, there was a consensus that taking vitamins was important.

What are some things women should do while pregnant to stay healthy?

Only two groups of women without children were able to answer this question due to time constraints. The two things both groups stated were taking (and being able to afford) prenatal vitamins and attending prenatal care visits. Other important factors to stay healthy during pregnancy mentioned by women in the groups were: to not make a lot of changes, “after third month, should exercise [because it is] easier to deliver if you’re healthy,” eat healthy, “educate herself about all the things that [she] will need to know after the baby is born, [such as] safe sleep,” having a plan, and eliminate stress.

For those women who were pregnant or already had children, many of the suggestions were similar. Among the young mothers, several group members mentioned they did not know they were pregnant for months and, therefore, did not get prenatal care for months. Almost all mentioned that their mothers knew they were pregnant before they had a positive pregnancy test. Suggestions from the groups of mothers that responded to this question included: take vitamins (or folic acid), have a good Body Mass Index (BMI), check your cholesterol and blood pressure, be in good physical condition, don’t smoke, exercise and stay in shape, make sure your partner and you are safe (free from HIV and STD’s), don’t drink alcohol, and eat right.

[Only women who had been pregnant answered this next subset.]

Was your first pregnancy planned? Why or why not?

Not all groups answered this question, those without children and some groups with children skipped this one. Among the women who responded that their first pregnancy was not planned, many said it was due to lifestyle changes (new job, had not gotten pregnant after trying for a long time); some reported they simply “didn’t think about it- never thought about it” or merely stated they were “young.” For some, a lack of birth control or a lack of understanding about how their method worked best, how antibiotics interfered with birth control, and correct method usage were the main reasons they had an unplanned pregnancy. One participant reported thinking she could not get pregnant.

What did you do when you were pregnant to stay healthy?

Almost all of the groups listed taking their prenatal vitamins, going to the doctor for their prenatal care visits, and “eating right.” Many groups listed exercise as part of their pregnant lifestyle, and younger mothers discussed quitting smoking and drinking. One member of a focus group of young women mentioned she “stop[ped] partying.” Trying to get adequate rest and reducing caffeine intake were brought up in two group sessions. Other activities the women in

the focus groups did to stay healthy were read books and attend childbirth classes, avoid fatty or salty foods, refrain from drinking soda/pop, and drink water.

When do you believe a woman should talk with a health provider about her pregnancy?

Women within focus groups and across focus groups had varying ideas of when a woman should talk with her health care provider about her pregnancy. Four groups mentioned that women should see a doctor before becoming pregnant, as one woman stated “prenatal care also begins before conception.” One member of a different group said “if she is planning a pregnancy and something is wrong.” Talking to the doctor as soon as the woman finds out was discussed in four groups, of which some conversations occurred in the same groups that mentioned preconception care. A few groups discussed beginning care in the first trimester. There was also the prevailing concept of talking to the doctor whenever something is wrong or the mother has concerns.

Did anything keep you from getting prenatal care as early as you wanted?

Among the groups of younger women (those under 24), the most common response was denial about pregnancy - “scared to admit I was pregnant,” not knowing about pregnancy until several months after conception, and then after that “nothing.” For other women in the focus groups, the issue of health care and money for care, and the fact that they had to “wait until pregnant to get health care” prevented some women from getting the care they wanted when they wanted it. A woman in one group mentioned work was a barrier for her to get prenatal care as early as she wanted. Another mother mentioned that it “used to be easier to get SoonerCare, [it] takes more time now if you don’t have a computer.” One of the women in one of the higher socioeconomic status (SES) focus groups couldn’t get in to see her doctor for three months and had to switch providers and another didn’t know she was pregnant until almost two months along because of false negatives on pregnancy tests.

What things did you know you should do but you didn’t or couldn’t? Why didn’t or couldn’t you do them?

The groups differed here based on age. Adolescent mothers stated things like fighting, with their boyfriend or other people, not taking their vitamins because they tasted bad or made them sick, drinking soda/pop, and just feeling sick in general. Mothers older than 20 mentioned exercise, eating healthy, making all their prenatal appointments, not following doctor’s advice on medications to take, giving up caffeine, getting enough rest, reducing stress, and lifting heavy things. When asked why they didn’t or couldn’t, responses ranged from feeling sick, being on medical restrictions, work, school, and taking care of other kids to “it’s easier with the first pregnancy but it gets harder when you have other kids.” Several women did say nothing but not many.

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

All women answered yes to this question. For many, being pregnant was a sort of call to action to become “more serious” about her health for the sake of the baby, as one participant said “pregnancy makes you think about someone other than you.” And most women agreed they were more eager and worked harder to be healthy during their pregnancy, took better care of themselves and were more cautious than before they became pregnant. One woman reported losing weight during pregnancy because of improved nutrition and eating habits.

When pregnant, who did you rely on for information about pregnancy, health, and babies?

The two most common responses given across the groups were the participants’ mothers and doctors. Books, friends, family, nurses, internet, the baby’s father, church, and grandmother were also given.

What kinds of things were stressful during your pregnancy? How did you handle this stress?

Relationships with significant others, the baby’s father, finances, how to handle an additional (or first) child, health problems, fitting into clothes, being emotional during pregnancy, work and transportation were all stressors discussed across the various focus groups. Most women handled stress in similar ways and found support from friends and loved ones, others researched problems and issues, set aside some time for themselves, and avoided negative people who “wanted to share their labor/other horror stories.”

How long should women wait before having another baby? Why?

The majority of groups had a consensus about the length of time to wait before having another baby. Most said at least two years, some were longer, three years, the youngest groups of mothers said 3-5 years so “the kids will be old enough to help” and “you don’t have two kids in diapers at the same time.” Only one woman stated a shorter interval 6 weeks, and one woman said 1-2 years. Two women brought up the issue of being able to afford another child as a motivation to space children. Most women who stated two years said it was so their bodies could heal and recover. Also the thought that you want time with your first baby, to bond and feel “stable” so that parents “know what they are doing” was mentioned in a few of the groups.

INFANT HEALTH:

Women with children answered this subset of questions. Women without children answered only a breastfeeding knowledge question and the infant mortality question. Not all groups answered this subset of questions, due to time constraints.

[For women without children]

What do you know about breastfeeding?

For women without children, there were differing levels of awareness about breastfeeding, although most women felt it was healthy for the child. Some women reported hearing it was painful and one participant said she knew some women who didn't want to because "they think if you breastfeed it doesn't give the father a chance to bond." Although other participants followed that up with he can "do the burping."

[For women with children]

Did you ever breastfeed your baby, even just one time? How did your family, friends, partner react?

The focus groups comprised of women with children were more aware of breastfeeding; many women had attempted nursing with varying degrees of success. Duration of nursing ranged from none at all to one year. Maternal age and ethnicity seemed to influence duration, groups with older mothers (25 years plus) or Hispanic mothers tended to state longer and more successful breastfeeding. The younger women reported being embarrassed by leaking, having a painful experience if they tried, not making enough milk, and some stated it just did not feel right to have the baby sucking. One young mom stated "I quit because I didn't know what I was doing." Among the older participants, women who tried it stated they "loved it," some experienced problems with milk supply and some who were pregnant at the time of the focus group were planning to breastfeed their next infant. American Indian mothers reported modesty was an issue, either their own family members felt they should have been more private about breastfeeding or people they knew who breastfed were not "modest with their breastfeeding" and it was a problem. Many women stated they felt supported in their decision to breastfeed. Some of the younger mothers stated their partners wanted them to breastfeed. Several women in different groups said they did feel like those outside their family and friends were not supportive of their breastfeeding. They reported feeling stared at in public and one woman stated she knew someone who was mocked by her coworkers for breastfeeding.

Were there any changes after the baby was born, in your body, your life, that surprised you or that were unexpected?

Most groups agreed that the physical changes in a woman's body after delivery were unexpected, the change in weight and metabolism, and the change in their breasts. Another commonality between the groups was the unexpected stress that being a new mother can bring into your life. For some women, the stress impacted their own health, for others it impacted their mental health. For the younger women, the added combination of motherhood with school caused additional complications. Some women reported more positive changes, the loss of their baby weight quicker than expected, and "all the love inside of you for your child before it happens, how it

will change your whole life, unbelievable connection to the baby.” But overall, either good or bad, one sentiment was prevalent “I thought I knew what to expect but I didn’t.”

Where did you get your information about how to care for your baby?

Most groups agreed that their mother was their primary source of information about how to take care of their baby. In the group of younger moms, many stated they already knew how to take care of their babies because they had raised younger brothers and sisters. Several groups mentioned nurses at the delivery hospital, their doctor, or the baby’s pediatrician; a few mothers mentioned the internet and books on pregnancy and infant health. Some women reported they took childbirth or parenting classes which were helpful. One woman said she learned by “trial and error” and another stated after the first child “you just know.” Some women were participants of different home visitation programs for new mothers and they indicated they received helpful information from them.

Who taught you how to lay your baby down to sleep?

Their own mothers and books were the two most commonly cited sources of information for the focus groups. Several women in different groups mentioned letting the baby “decide” how best to lay him/her down for sleep. Television was also a source of education; the Spanish speaking group cited information they received on Univision (Spanish language television) about how babies should sleep to prevent infant death. Grandmothers only came up in one group of younger women. Those with other children stated they learned from laying them down to sleep. Doctors were also cited as sources of information, but not always in a positive light. One woman said her doctors “recommended something different with all three of mine – stomach, side, and back.”

What does the term “infant (baby) safe sleep” mean to you?

Most participants in the focus groups knew that it was safest for baby to sleep on his/her back, without blankets and pillows, and some groups mentioned that baby should sleep alone. However, there were also many comments about how some of the mothers did not follow this advice. For example, one young mother reported her baby slept in her arms and another laid her baby on its stomach with a pillow underneath. Again, there appeared to be a difference in response according to age and socioeconomic status (SES) level. Groups with older women with higher incomes tended to understand the meaning of safe sleep and follow through better than their younger, lower-income counterparts.

Did you or someone you know have postpartum depression? Did you/they get help? Was help available? How did their friends and family react to it?

The majority of groups discussed baby blues and postpartum depression almost interchangeably. Some of the younger women reported not knowing what postpartum depression was. Women in

the different groups reported that if they or someone they knew had it, there sometimes wasn't much help available or they didn't know where to get the help they needed. One woman discussed her friend's experience: "She didn't have much help but eventually found help... [her] friends and family [were] not very supportive – she started having anxiety attacks which made her seek professional help." Among women who felt they did not have support from family or friends, symptoms were hidden and/or they felt resentment towards those who were not supportive.

Did you or someone you know have a baby that died before his/her first birthday? What do you think contributed to the baby's death? How did friends/family/community respond after the baby died?

All of the groups reported knowing someone who had experienced an infant loss. A variety of causes were discussed from birth defects, co-sleeping, Sudden Infant Death Syndrome (SIDS), baby not being able to breathe, drug abuse, car accident (with baby in mother's arms), stillbirth, and premature delivery. Some women felt there were genetic problems that caused the infants' deaths and in one case the participant felt the doctors were not attentive enough to the medical needs of the baby. All reported support and sympathy from the community for the families. One woman had a family member experience an infant death and said it is difficult because "you don't know how to help or what to say."

HEALTH DISPARITIES:

From what you see in your neighborhoods and communities, what do you think about the health of others who are also [African American/Black, Hispanic, white]? Does it seem better, the same or worse than average?

Overall there was a group consensus that African American/Black individuals experience worse health than average. Only the young African American/Black mothers felt it was better. The majority of the groups felt the issue of reduced access to health insurance or health care contributed to this problem in their neighborhoods. Income was seen as the primary indicator of health care access. One group stated "People who have more money tend to be healthier" because "more money gives you more resources." The levels of safety in their communities and neighborhoods, as well as, the opportunities available for residents were also cause for concern.

What things exist in the neighborhoods where you live and work that help or hurt someone's health?

Groups were in agreement on the things in a neighborhood that hurt health such as gangs, violence, drugs, liquor stores everywhere, lack of access to grocery stores, and lack of health care in the neighborhood. As one participant stated that without nearby grocery stores "it's hard

when you're craving to get something good to eat – to satisfy your cravings.” Things that were reported by the groups to help encourage healthy behaviors were sidewalks and walking trails, playgrounds, feeling safe, and having others to encourage you to walk and be active. One younger woman felt her neighborhood did not affect her health.

Do you think there are differences in the health of African American/Black people versus white people? Talk about what you see between African American/Black and white (Hispanic, etc.) people in terms of how they get healthcare and why there may be differences (if you think there are differences).

Most groups (and not all groups had an opportunity to answer this question) felt there were differences based on race or culture. Some individuals did not perceive a difference and the group of young African American/Black mothers did not feel comfortable discussing this question with their white facilitators and so they did not offer any comment. For those who did answer and felt there was a difference, many stated it had to do with insurance access. “Most black people don't seem to have insurance” or they are unaware of the health care they can get. Others felt maybe preventive health care was not always a priority; they would wait until they were sick because they needed their money to pay for different needs. Some groups felt that the American Indians in the state had better health outcomes because they had “free insurance” from their tribes. The disparity in wealth and jobs with benefits was also perceived to be a contributor to the differences in health status between African American/Black and white people. One group felt that for Hispanics, age was important; the younger people were healthier than the older people.

What would you do to improve the health of African American/Black people (Hispanic, etc.) in your neighborhood if there were no obstacles to doing it? Why do you think that would work?

For many of the groups (and not all groups had an opportunity to answer this question) the main thing they would do to help improve health is increase the number of health care providers in the communities where they live and work. Several groups offered ideas to further this, such as door-to-door doctors and health messages, free checkups for preventive health issues, the need for clinics where people live, go, and where they feel safe. One group stated that people can't trust doctors based on history so there is a need to recruit more minority doctors. Groups offered advice such as place more emphasis on sex education and reproductive health classes for high school students, but to also make this available in churches. Face-to-face conversations, messaging, and personal and home based health care were important factors in improving health status because as one woman stated “I'm more likely to believe something if someone is talking to me face-to-face.”

5. IMPLICATIONS AND LESSONS LEARNED

Several important themes resonate throughout this document and the discussions facilitators had with participants. The first is that while access to health care is available to some women and their families, women don't always take advantage of the services. This is due to a variety of reasons, including time, severity of health concern, customer service received at a provider in the past, and cost. There was an overwhelming desire to be treated with respect and compassion, to not feel rushed, have a medical home, and be given appropriate education by their health care providers. Most women with negative health care experiences related it back to a poor bedside manner and poor customer service from a previous health care provider. The women in the focus groups also had very disparate ideas of how often a person should have a checkup. The issue of preventive health care did not seem important, as many women reported only going to the doctor when sick or pregnant. The primary barrier to access was a lack of health insurance or money, and most women reported if health insurance coverage was better and more affordable throughout their communities, health would improve.

The groups talked about differences in health equity, though that specific term was never used during conversation. For example, the groups perceived differences in the standards of care among women of differing races or ethnicities. American Indian women were seen as having "free insurance" through Indian Health Services/tribes. The disparity in wealth and jobs with benefits was also perceived to be a contributor to the differences in health status between African American/Black and white people. One group felt that for Hispanics, age was important; the younger were healthier than the older people.

Stress and stressors are ubiquitous in this report. Stress impacted all of the women in different ways: financial worries, relationships, work/school, time constraints, family commitments, health concerns, and becoming a new mother (or a mother again). Women reported that stress impacted their physical and mental health. Throughout these conversations, the woman described several ways that they reduce the stress of pregnancy, such as taking it day by day, talking to supportive people/spouses, not listening to negative people who wanted to share labor/other horror stories, read books for correct information about pregnancy, relying on a spouse for understanding and advice, and taking time to relax. Clearly stress is a factor for all women regardless of age, race, or ethnicity. For future focus groups, one suggestion would be to add a question asking for specific stress reducing techniques that the women engage in both before, during, and after pregnancy.

The presence of men as a support system and source of information about health, breastfeeding, and infant care was greater than originally hypothesized by the workgroup. It should be noted, however, that every member of the workgroup was female. Health professionals need to be cognizant of their own beliefs, attitudes, and opinions regarding men and how they may

unknowingly create barriers for men in accessing and promoting health services and information. More research is needed in the areas of male and father involvement and the subsequent effects it has on maternal health, pregnancy, and infant outcomes.

Another theme identified from responses by the groups is the idea that health is a community effort, not something that the individual alone can control, motivate, or respond to in every instance. For example, although many women reported knowing how to stay healthy, eat nutritiously, exercise, take vitamins, etc., many stated it would take having someone else in their family, their neighborhood, or their social circle, to walk with, diet with, and help them become or stay healthy. The built environment, such as a lack of neighborhood grocery stores and an overabundance of liquor stores, was mentioned as a barrier to achieving a healthier diet. Things that were reported by the groups to help encourage healthy behaviors were sidewalks and walking trails, playgrounds, feeling safe, and having others to encourage you to walk and be active. The question for communities becomes one of how do you create social norms to establish a community of health, respecting individuals, but drawing on the collective strength of the neighborhood, church group or population to make lasting change?

Overall, facilitators reported that these conversations were enlightening. Insight into the clients we serve and the women we work with daily was gained in unexpected ways. Women were involved, and even enjoyed, this opportunity to talk about their ideas and feelings about health.

6. RECOMMENDATIONS

PROVIDERS

1. Observe tenets of excellent customer service in every aspect of the clinic or office experience.
2. Define what constitutes preventive health care for women and men, emphasize the content, timing, and how and where to access it in local communities. Provide this education to males and females at an early age.
3. Tailor messages to an individual's life situation and beliefs, to keep them engaged in the discussion about their health and well-being.
4. Involve women's partners and families in health care discussions, incorporating those individuals they rely on for health care information outside of professional circles. Develop health materials for multiple audiences (mothers, partners, grandparents, etc.) about health issues that impact reproductive-aged females and males.
5. Promote available resources for family planning and birth control where adolescents and young adults live and work.
6. Promote appropriate and consistent condom use among adolescents and young adults.
7. Involve males in health education efforts about healthy pregnancy, healthy living, breastfeeding, infant safe sleep, etc.
8. Solicit and incorporate patient and community feedback to improve services and access to care.
9. Recruit, hire, and train health care providers who live in and belong to the communities they serve.
10. Promote SoonerCare and the Family Planning Waiver to all clients so they can receive free or reduced cost family planning services.

AGENCIES AND SCHOOLS

1. Observe tenets of excellent customer service in every aspect of the clinic or office experience.
2. Support and promote peer education programs for healthy behaviors and adolescent pregnancy prevention.
3. Collaborate with non-traditional partners, such as grocery stores, laundry mats, and churches to get information about health and health care services out into the communities in need.
4. Coordinate efforts with other agencies so that partnerships can be created to help populations learn about health. For example, provide health education to clients waiting for appointments at social service agencies.
5. Utilize strategies to relay information in culturally appropriate, evidence-based ways, to target interventions where people live and work.
6. Develop trainings and fact sheets for clergy and other lay health educators for preconception health behaviors to incorporate into church bulletins, premarital counseling sessions, appointments, etc.
7. Incorporate preconception health into evidence-based health education curricula in schools to reinforce the importance of health across a lifespan, and how it impacts health across generations.
8. Create internet resources that are easy to navigate, easy to understand, and have eye-catching pictures.
9. Create more awareness of the Tobacco Helpline and provide evidence-based tobacco and substance use prevention curriculum in schools.
10. Encourage schools to become Certified Healthy Schools.

COMMUNITIES

1. Support community initiatives centered around preconception and pregnancy health; such as Community Baby Showers, Fetal and Infant Mortality Review (FIMR) Community Action Teams, town hall meetings, and other community-driven events.

2. Create opportunities for females to learn simple and free or low cost stress reduction techniques.
3. Create more awareness of the Tobacco Helpline and provide community education about tobacco and secondhand smoke on health, pregnancy, and children.
4. Provide accurate and up-to-date information to community members about health and healthcare providers through information assistance lines such as 2-1-1.
5. Encourage more businesses to become Certified Healthy Businesses.
6. Encourage communities to become Certified Healthy Communities.

POLICY

1. Support the creation of a “Preconception Health Awareness Day” in Oklahoma and nationwide.
2. Support and fund programs like Family Expectations, Children First (C1), Oklahoma Child Abuse Prevention (OCAP), Healthy Start, and others which provide evidence-based health education and mentoring for first time mothers.

7. ACKNOWLEDGEMENTS

To the 75 women who participated in these focus groups, the Preconception/Interconception Care and Education Workgroup would like to extend our heartfelt thanks and gratitude for your time, your ideas, and your words. May you and your children, both current and future, be healthy.

To the facilitators and note takers who made these groups a reality, thank you for your time, your patience, and your due diligence to help improve the health of women and children in Oklahoma.

To the members of Preconception/Interconception Care and Education Workgroup, thank you for your help revising the tool, reviewing the data and information, and writing the report.

To the [North Carolina State Infant Mortality Collaborative](#) for allowing us to use your questionnaire and survey information and for taking the time to discuss with us your work with the women of North Carolina.

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This and other “Preparing for A Lifetime, It’s Everyone’s Responsibility” publications can be found on the web at: <http://iio.health.ok.gov>



An AA/EEO Employer

8. APPENDIX

Appendix A: Survey

Appendix B: Consent

Appendix C: Questionnaire

Appendix D: Training Powerpoint

Appendix A

Survey

Survey of Focus Group Participants

1. What kind of health insurance or medical coverage do you have?
 - Private insurance
 - Medicaid (SoonerCare or SoonerPlan)
 - Medicare
 - Indian Health Service (IHS) or Tribal
 - 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. Do you have any children?
 - No - **Go to Question #7**
 - Yes
6. What are your children's ages?

7. What year were you born?

8. Which of the following best describes your relationship status? (*Select one.*)
 - Single
 - Living with significant other (not married)
 - Married
 - Separated
 - Divorced
 - Widowed
9. What is your highest level of education?
 - Middle or elementary school
 - 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 annual **household** income?
 - Less than \$15,000
 - \$15,000-\$29,000
 - \$30,000-45,000
 - \$45,000-\$60,000
 - Over \$60,000
11. How would you identify your race? (You may select more than one.)
 - American Indian
 - Asian
 - Black or African American
 - White
 - Other _____
12. How would you identify your ethnicity? (Select only one.)
 - Hispanic or Latino
 - Not Hispanic or Latino
13. What is the postal zip code at your home? _____

14. Have you ever been pregnant?
- No -Thank you! You've completed the survey.
 - Yes. - Go to Question #15
15. How many times have you been pregnant? _____
16. How many live babies have you given birth to? _____
17. Have you ever had a stillbirth (baby born dead near full-term), miscarriage, or abortion?
- No
 - Yes
18. Have you ever had a premature birth (baby born more than 3 weeks before your due date)?
- No
 - Yes
19. Have you ever had a low birth weight baby (baby weighed less than 5lbs. 8oz. or 2.5 kilograms at birth)?
- No
 - Yes
20. Have you ever had a baby die during its first year of life?
- No
 - Yes
21. 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 Oklahoma.

Appendix B
Informed Consent

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 Oklahoma State Department of Health (OSDH) and our partners to improve their public education campaigns. The information will also be used by researchers and the OSDH to prevent deaths of infants and 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 1 ½ hours to 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 tote bag with thank you items inside 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.

Your name will not be recorded on any notes or documents. 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.

By staying in the room and participating in the focus group you are giving us permission to use your comments and survey information in our reports.

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

If you have questions about this focus group, you may call Jill Nobles-Botkin, Director of Perinatal and Reproductive Health, at 405-271-4060.

If you have concerns about your rights as a participant in this focus group you may call Malinda Douglas, IRB Administrator, at 405-271-4072.

Appendix C
Questionnaire

FOCUS GROUP QUESTIONNAIRE

1. What does Healthy mean?

What does health mean to you?

What (if any) is the difference between looking healthy and being healthy?

What would you tell someone else about being healthy or staying healthy?

2. Preventative Health Behaviors

What things do you know you should do to stay healthy? [Make a list on flipchart {sometimes dental health is overlooked}]

What are some things you know you should do to stay healthy but you don't?

What would motivate you to practice some of those healthier behaviors?

What keeps you from doing those things to stay healthy? [Probe for internal and external factors like lack of access to health care system, transportation, lack of health insurance, lack of money, motivation, feelings, etc.]

What advice did your mother or grandmother give you about staying healthy?

3. Health Information & Advice

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

How do you like to get information about your health? How can you tell if it's trustworthy? [probe for websites, dr., friends, family, news media, etc.]

If you go to websites or read health brochures and magazines, what about them attracts and keeps your attention?

4. Preventative Health Care Services

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

How often/when should people go to the 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/staff, family members, motivation, feelings, etc.]

Describe a positive experience with a health care professional, like a doctor, nurse, lab technician, etc.

Describe a negative experience with a health professional.

How well do you understand what the doctor/nurse says about your health or treatment?

When you go to the doctor/clinic, do you feel comfortable asking questions? Why or why not?

If you could change something about your experiences with health care professionals, what would it be?

5. Family, Friends and Relationships

How do your relationships influence or affect your health? [probe: domestic violence]

How would you describe a "healthy family"?

Have you or anyone in your family used alternative or herbal medications? If yes, what were they and what were they used for? [Probe: What was their mom's/family's favorite home remedy?]

6. Pregnancy and Reproductive Health

What does the term "healthy pregnancy" mean to you?

What kinds of things should a woman do *before getting pregnant* to have a healthy pregnancy? [Probe: folic acid, stopping smoking, drinking]

What are some things women should do while pregnant to stay healthy?

[For groups with women who have been pregnant]

Was your first pregnancy planned? Why or why not?

What did you do when you were pregnant to stay healthy?

When do you believe a woman should talk with a health provider about her pregnancy? [probe: weeks or months pregnant, when should prenatal care begin].

Did anything keep you from getting prenatal care as early as you wanted? [probe for external and internal factors, money, transportation, motivation]

What things did you know you should do but you didn't or couldn't? Why didn't or couldn't you do them? [probe for external and internal factors, money, transportation, motivation]

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

When pregnant, who did you rely on for information about pregnancy, health, babies?

What kinds of things were stressful during your pregnancy? How did you handle this stress? [probe: What did you do to reduce/relieve it?]

How long should women wait before having another baby? Why?

7. Infant Health and Care

[For women without children]

What do you know about breastfeeding?

What does the term "infant (baby) safe sleep" mean to you?

Where would you get information about how to care for a baby?

Did you or someone you know have a baby that died before his/her first birthday? What do you think contributed to the baby's death? How did friends/family/community respond after the baby died?

[For women with children]

Did you ever breastfeed your baby, even just one time? How did your family, friends, partner react? [Probe: support, help, frustrations]

Were there any changes after the baby was born, in your body, your life, that surprised you or that were unexpected?

Where did you get your information about how to care for your baby?

Who taught you how to lay your baby down to sleep?

What does the term “infant (baby) safe sleep” mean to you?

Did you or someone you know have postpartum depression? Did you/they get help? Was help available? How did their friends and family react to it?

Did you or someone you know have a baby that died before his/her first birthday? What do you think contributed to the baby’s death? How did friends/family/community respond after the baby died?

8. Health Disparities

From what you see in your neighborhoods and communities, what do you think about the health of others who are also [African Am., Hispanic, white]? Does it seem better, the same or worse than average?

What things exist in the neighborhoods where you live and work that help or hurt someone's health?

Do you think there are differences in the health of African American people versus white people? Talk about what you see between African American and White (Hispanic, etc.) people in terms of how they get healthcare and why there may be differences (if you think there are differences).

What would you do to improve the health of African American people (Hispanic, etc.) in your neighborhood if there were no obstacles to doing it? Why do you think that would work?

Appendix D
Training PowerPoint

Preconception and Pregnancy Health Focus Group Training



Purpose:

- The purpose of this study is to assess what women know, need to know, and how they learn about pregnancy health during their reproductive years.
- Currently OSDH and partners collect primarily quantitative data on women of reproductive age however qualitative information, such as how and why the statistics report what they do is largely left unanswered.



Focus Group Logistics

- Need at least two people for each focus group
 - One facilitator
 - One note taker
- Instrument
 - Specific questions will be provided to each note taker / facilitator.
- Incentives
 - Each participant will receive a gift card or a tote bag with books, CDs, etc. for their participation.





Reporting Your Findings

- Identify sub-themes indicating a point of view held by participants with common characteristics
- Use descriptive phrases or words used by participants as they discussed the question.
- Include a description of participant enthusiasm or other group characteristics if relevant
- In giving meaning to the descriptions, be careful about your own biases in interpretation
- Summarize the overall mood of discussion.
- Suggest new avenues of questioning that should be considered in future: should questions be revised, eliminated, added, etc.



Focus Group Basics

“The hallmark of focus groups is the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group (Morgan, 1997).”



Focus Group Basics

Focus groups are usually:

- Held with a group of ten to twelve people
- Participants are homogeneous on the basis for recruitment but unknown to each other
- Led by a facilitator in a group interview format
- Of 1 ½ to 2 hours in duration.
- Used when largely qualitative information is required
- Produce qualitative data - the goal is not to reach a consensus, solve a problem or make a decision.
- Seek to obtain insights into attitudes, perceptions, beliefs and feelings of participants.
- Questioning route uses predetermined, sequenced, open-ended questions.

Focus Group Basics

Focus groups are appropriate methods to use for:

- identifying needs and expectations
- obtaining regular “snap shots” of an experience
- testing attitudes to proposed service enhancements or new methods of delivery
- probing for perceptions and experiences relating to a particular experience or program
- obtaining feedback on a recently introduced initiative
- getting feedback for improvement
- understanding how participants think
- identifying key issues that should be addressed in a quantitative survey
- obtaining more detail about service gaps identified in quantitative research.



Ethical Issues

There are a number of ethical issues that focus group facilitators need to be aware of and to address appropriately. The most important are:

- The voluntary nature of focus groups
- The need to respect confidentiality and anonymity.



Consent

No person should be compelled to participate in a focus group, nor should they be made to remain if they want to leave. Consent should be obtained from each participant prior to the focus group, and a clear statement of the purpose of the focus group should be provided, to allow prospective participants to make an informed decision.

No use should be made of the information provided in a focus group other than for the purpose for which consent was given.



Obtaining Participant Consent

Inform the participants that if they do not wish to be involved in the focus group now is the time that they should excuse themselves. Ask the participants to introduce themselves and by doing so you are giving consent to participate in the focus group. Have them sign the document of informed consent and ask them to turn in their brief surveys.



Confidentiality

People who participate in focus groups must be assured that **no information will be revealed that can identify them, and that comments they make are not reported (either verbally or in writing) in such a way that specific people or incidents can be identified.**

People will either not participate in a focus group if they are not given that assurance, or they may distort or suppress information if they feel it is going to be used for other purposes.



Confidentiality

In addition to these two key issues, the actual conduct of focus groups requires attention to more subtle matters of ethics. In conducting a focus group, facilitators need to:

- Avoid judging focus group participants by their appearance or other known characteristics
- Treat all people and the comments they make with respect
- Avoid influencing a response by asking leading questions
- Observe confidentiality with focus group discussions so that minimal information is revealed that could be used to identify personal details of focus group participants or any people to whom they refer.





Conducting focus groups

Preparation

- Ensure the room is comfortable and that the seating allows participants to see and interact with each other
- Select two people to conduct each focus group
- Agree who will take lead interviewing role and who will take notes and keep time
- Bring with you a copy of any correspondence to the participants, consent, surveys, etc.
- Ensure you understand each of the questions being asked from the provided questions given to you.



Conducting focus groups

General discussion

- Greet each participant and start the session with introductions.
- Open by thanking the group for their time
- Introduce yourselves and group members – quickly!
- Restate the purpose of the focus group, the beginning and ending times, and the respective roles of the two facilitators – i.e. one to manage the discussion and one to take notes
- Make a clear statement about confidentiality– no statement made will be attributed to a particular person and no identifying details – about both participants and any people referred to – will be disclosed



Conducting focus groups

- Ask group members to respect each others' confidentiality too.
- Ask if they have any questions before you start. Keep further explanation brief and to the point
- Remind them of the main purpose of the focus group – to collect information about the issue
- Explain what will be done with the information after it is collected
- Encourage discussion but keep the pace moving, to be sure you cover the areas you wish to cover
- Ensure all members to participate, especially about more complex issues.
- Encourage those who talk less to share their thoughts and don't allow one or two members to dominate the sessions.

Conducting focus groups

- Ensure all participants have reasonable airspace; invite quiet members to comment
- Ensure the discussion is focused on key elements of the questions.
- If your interview is concluded without having learned about the most important aspects from the participants' point of view, it has failed to achieve its purpose.
- Don't concentrate on one topic at the expense of others.



Conducting focus groups

- If you begin to run out of time, there are several options. (You will need to be sensitive to the atmosphere and room needs in order to propose the best option):
 - ask if you can extend the current interview time
 - work quickly through the key questions in the remaining time
 - finish before having all your questions answered



Conducting focus groups

Note-taking

- Both facilitators may take brief notes, but one should have primary responsibility for note taking
- Notes should summarize the key points being made by focus group participants
- Try to record the comments in the appropriate space of your interview schedule so that minimal sorting has to be done later
- Avoid bias; ensure comments are recorded accurately and objectively
- Where there is agreement between several group members on an issue, just tick the comment by the number of people who agreed (even nonverbally) to it
- Record good quotes verbatim, as they can provide a flavor to the report



Conducting focus groups

Closure

- Summarize the key issue raised and key points made
- Repeat what actions will be taken as a result of their feedback, and how this will be communicated
- Thank the group for their time and input

Follow up

- Clean up and clarify your interview records immediately so that they can be understood at the report writing and collating stage.



Scenarios

What would you do if...

- One participant is doing all of the talking...
- A mother is complaining at length about her bad experience with the Health Department...
- One participant has not said a word for 20 minutes...



Reporting Your Findings

- Identify sub-themes indicating a point of view held by participants with common characteristics
- Use descriptive phrases or words used by participants as they discussed the question.
- Include a description of participant enthusiasm or other group characteristics if relevant
- In giving meaning to the descriptions, be careful about your own biases in interpretation
- Summarize the overall mood of discussion.
- Suggest new avenues of questioning that should be considered in future: should questions be revised, eliminated, added, etc.



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