

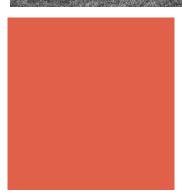


**Formative Research** 





Texas Department of State Health Services March 2019









### Healthy Texas Mothers and Babies Communication Campaign: Formative Research

SUMA Social Marketing, Inc. prepared this report

for

Texas Department of State Health Services





SUMA Social Marketing, Inc.

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### **Executive Summary**

SUMA Social Marketing (SUMA) conducted qualitative research for the Department of State Health Services (DSHS) and the Health and Human Services Commission (HHSC) in order to improve the DSHS *Healthy Texas Mothers and Babies* (HTMB) initiative to deliver preconception and interconception health information.

The research goals were to:

- Assess lessons learned from previous campaign marketing and outreach efforts.
- Determine the most effective preconception, maternal, interconception, and infant health and safety messaging and communication strategies to educate and empower the target populations.
- ◆ Determine key elements of, and new direction for, the marketing and outreach strategy of the campaign, including its reframing and rebranding.
- ◆ Further define and analyze the target audiences with a specific focus on the knowledge, attitudes, and practices of preconception women ages 18–25, interconception women with two or more children under five, women who have had a high risk pregnancy in the past two years, fathers of young children, preconception men ages 18–25, labor and delivery nurses who support women who have a high risk pregnancy during birth and immediately postpartum, healthcare providers including physicians in family practice and OB/GYNs as well as nurse practitioners and certified midwives .
- Determine optimal message development, content, design, and delivery for preconception, interconception, high risk pregnancy, and provider messaging that is compelling and resonates with the target audiences, and presented in an appealing, accessible format.
- Maximize the input and engagement of key stakeholders—healthcare providers, professionals, the HTMB initiative's existing and potential partners, and others—who can support outreach and serve as champions and influencers for community and systems-level improvements.

From October 2018 to December 2018, SUMA conducted research in the communities of Dallas, San Antonio, Tyler, Amarillo, Beaumont, and Laredo, all of which have active HTMB coalitions. All focus group participants (other than healthcare providers and nurses groups) were screened to ensure their annual income was at or below 200% of Federal Poverty Level.

#### The research included:

- ◆ Focus groups with preconception women ages 18–25 (N=5), interconception women who had two or more children under the age of five (N=5), women who had a high-risk pregnancy within the past two years (N=5), preconception men ages 18–25 (N=2), fathers of young children (N=3), labor and delivery nurses (N=3), and healthcare providers (N=3).
- ◆ In-depth interviews with key stakeholders (N=10) and HTMB coalition members (N=15).
- ♦ Engagement with 228 participants in total across focus groups and interviews during study.
- ♦ A high-level national review of existing campaigns related to preconception, interconception, maternal, and infant health as well as campaigns and initiatives targeting similar audiences to learn from what has already been done and to select materials to test in focus groups.

### **Summary of Findings**

SUMA researchers collected and analyzed the diverse and detailed perspectives, experiences, and insights from the participants to derive a number of key findings and achieve the research goals. While some findings were unique to one target audience, several findings and themes were consistent across groups. These overarching findings are described below.

Participants are unaware of birth spacing recommendations and do not know of the benefits. None of the women in the interconception groups or the fathers of young children were aware of the Centers for Disease Control and Prevention (CDC) recommendation to wait at least 18 months between giving birth and getting pregnant again. They were also unaware that a shorter pregnancy interval increases the risk of poor birth outcomes. Furthermore, medical providers did not educate about this recommendation or the importance of it for healthy birth outcomes. Healthcare providers and other participants were receptive to the educational resources on birth spacing presented in the groups; these offer information about the value of birth spacing and the potential for poor outcomes for the birth or infant as well as for the physical and mental health of the mother, finances, relationship health, and current children if births are spaced too closely.

Many participants lack access to healthcare. The majority of men and women in the focus groups did not have health insurance and could not afford to access preventive care such as well woman exams or yearly physicals. Most did not seek care unless it was an emergency. This was particularly problematic for the many women in the interconception and high-risk pregnancy groups who reported significant complications from their pregnancies or had ongoing chronic conditions. Many were unable to address these conditions beyond a single postpartum visit since they lost their Medicaid coverage 60 days after giving birth. This finding was corroborated by the labor and delivery nurses and healthcare providers. Even for those who have Medicaid coverage, access is further complicated by a lack of specialists who accept it and a lack of specialists in rural areas overall. The result was that many participants who needed healthcare were unable to access it.

Limited family planning and birth control knowledge is the norm. Many focus group participants—regardless of if they were in the preconception or interconception phase, or were male or female—lacked birth control knowledge and reported that family planning is not a common behavior. The research supports the fact that education about birth control from a trusted source is limited. The primary place women said they learn about birth control is from healthcare providers or clinics, and men said their primary source of birth control information is their wives or girlfriends. Findings support the fact that it is difficult for providers to offer comprehensive birth control education during a single visit, and not all doctors are able to cover the full range of details during prenatal care or well woman exams.

A notable number of women said that their visits to healthcare providers often felt rushed and they left with unanswered questions, which prevented them from making a birth control decision or fully understanding their options. Others described providers as "pushy" about birth control, which made them feel uncomfortable and suspect an ulterior motive. Some women (and a few men) spoke of unpleasant side effects or failed birth control, which impacted their trust and desire to use it. No one reported a trusted go-to source for birth control information except for a few women who mentioned Planned Parenthood.

While healthcare providers reported offering birth control education at well woman exams, and in prenatal or postpartum visits, they also reported seeing an average of 20 patients a day and admitted that their time with each patient is limited. Access to birth control information is further limited in some communities where Catholic hospitals and clinics are major healthcare providers because staff are not allowed to discuss or provide birth control in any way.

Timing and tone of birth control information is also important. Some interconception women said they were not receptive to birth control information immediately after birth, either because of fatigue or because it seemed incongruent with the emotions they were experiencing in welcoming a new baby. Some men and women were resistant to birth control questions at this time as they did not receive any larger context about birth spacing and family planning during the conversation. Regardless, the postpartum period is a common time for birth control education and decision making.

The online and print educational materials about birth control that were tested in the groups and contained straightforward information on birth control options, costs, and the pros and cons of each option were well received by both women and men.

Preconception and interconception audiences prefer streaming services and social media rather than traditional cable or radio. It was clear from the responses that traditional advertising campaigns that rely on network or radio advertising will not reach these audiences. For the most part, they do not watch cable television or standard networks or listen to traditional radio. They use social media and streaming options for entertainment. Pandora, Spotify, Netflix, Hulu, and You Tube are popular. The majority of participants also have active Facebook accounts, and many use Instagram, Twitter, and Snapchat as well, with the younger audiences especially spending significant amounts of time on these platforms on their phones each day.

# Google, mom, and Facebook are the primary places men and women in preconception and interconception audiences turn to for health information.

Participants in all groups reported turning to their mothers, Google, or Facebook when they have a medical question or concern. Very few, other than women in the high-risk pregnancy groups, reported turning to healthcare providers about health concerns. Many also use health- and wellness-related apps.

Mental health concerns, such as postpartum depression, general depression, and anxiety, are widespread. Resources for help are lacking. The interconception and high-risk pregnancy groups had a concerning number of women who reported various levels of postpartum depression. Participants also reported hesitancy to contact a healthcare provider for fear of losing their children or being judged as "unstable." Men also expressed concerns about mental health and how to access care. The healthcare providers reiterated that there are few resources for treating mental health symptoms and conditions, but that a significant portion of their patients report mental health struggles. They also reported a shortage of psychiatrists, especially for the Medicaid population. Some providers offer (psychiatric) treatment themselves, and some make referrals to counselors.

Women expressed dissatisfaction with provider care. Preconception, interconception, and high-risk women all commented that their healthcare appointments seem rushed, they spend a long time in waiting rooms, and/or they feel their concerns have been brushed off or not taken seriously by their providers. The few men who did receive non-emergency medical care reiterated this finding.

There is some awareness about safe sleep practices. Fathers and mother were aware of safe sleep messages that babies should sleep on their backs, alone, and in a crib free of blankets and stuffed animals; some admitted that they often sleep with the babies anyway for nighttime feeding convenience. No one knew of the connection between breastfeeding and reduced chances of Sudden Infant Death Syndrome (SIDS).

**Connections are key.** Participants across focus groups, especially women, noted how the opportunity to connect during the focus groups with others who had experienced some of the same challenges was in itself a mental health benefit and made them feel less alone. They also noted that Facebook groups offer some of this same connection.

### **Specific Findings for Target Audiences of Campaign Efforts**

### Preconception Women (ages 18-25 without children)

STDs, mental health, and birth control were top health concerns of this audience as is managing daily stress. Approximately half of the participants did not have health insurance. There was mixed knowledge about well woman exams and some participants were unfamiliar with the term or what was included in the exam. There was a lack of knowledge about where to access affordable care, and participants often learned from others in a focus group about clinics or programs. Only one woman in the entire study was enrolled in the Healthy Texas Women's program and she was in the preconception group.

Overall, campaigns and messages aimed at a future pregnancy did not resonate with these participants. They are more interested in age-specific information relevant to their own health and current lifestyle, including content about birth control, menstrual cycles, relationship health, vitamins, and self care, to name a few. While the best place to reach this audiences is online, some said they also like print pieces as a "starting point" or for easy reference as well.

### Interconception Women (women with more than one child under age 5)

The top health concerns for this audience included anxiety, depression, and various chronic conditions. Many have not been able to access care for these conditions because they do not have health insurance and/or are unaware of

where to access affordable care in their communities. A lack of education about birth spacing, combined with barriers to accessing birth control, is creating closely spaced, unplanned pregnancies and poorer birth outcomes.

Most of the interconception women had attended a postpartum visit, were asked by their provider then about breastfeeding, and received a well woman exam. Discussions revealed that many of these women had also experienced a variety of high-risk conditions and symptoms related to pregnancy and childbirth that emerged or became exacerbated after the initial postpartum period. Interconception women were often unable to seek care for those medical needs due to a lack of insurance, the effect of persistent mental health symptoms, or other barriers.

### Women with High Risk Pregnancies (one or more high-risk pregnancy in past year)

Women in these focus groups had a wide range of high-risk conditions and pregnancy-related or ongoing medical needs. They often did not feel as if they had received the information, preparation, support, and follow-up they needed to understand and effectively manage their risk conditions throughout pregnancy, birth, the postpartum period, and beyond. While all reported receiving some type of educational resources during their prenatal and postpartum care, these were rarely specific to the high-risk conditions. While some women had strong relationships with healthcare providers, most did not. As a result, these women often sought support from other mothers who had a similar experience, family, or Facebook. Many did seek limited additional healthcare, but often it was not the comprehensive care they needed because they could not afford it, did not understand the importance of continued care, were too busy caring for newborns and other children, or a specialist wasn't available or affordable. In the case of postpartum depression, many were afraid to seek help.

Women with high-risk pregnancies were eager to learn more from healthcare providers, trusted online forums and resources, and their peers. All women in these groups responded extremely favorably to the Post-Birth Warning Signs flier created by AWHONN and wished they had received it. They said it clearly communicated important information that they would share with family members and that they would post it in their homes. Those that saw the charm incentive bracelet in Tyler also liked it and thought it would motivate them to seek healthcare and health education.

### Preconception Men (ages 18-25 without children)

The top health concerns of preconception men were STDs and workplace injuries. They also said they are interested in learning more about birth control options instead of mainly relying on partners or limited methods. Participants liked the Bedsider birth control resources best of the materials tested.

Very few of these young men have insurance, and almost all only seek medical care in an emergency. Many men shared they learn healthy eating and exercise habits by following certain YouTube channels, Facebook groups, and Instagram accounts. They do not have people in their lives that they can or will turn to with health concerns, other than perhaps their mothers. While the "stay strong" mentality emerged in a few audiences (including with high-risk and interconception women), it was especially prominent among preconception men and fathers of young children.

### Fathers of Young Children (men with at least one child under age 5)

As with the other groups, many of these fathers are uninsured, which creates a barrier to healthcare. In the Laredo group, none of the participants were insured, and in San Antonio two men had insurance. A few more were insured in Tyler, but those with insurance struggled with high copays and costs. These men were only likely to get a physical if it was required for work and to seek medical care if they were extremely ill. It is notable that many of these men prioritize healthcare for their children even if they themselves don't receive it. Many of the fathers had attended at least one prenatal care visit with their partners, but very few went to a postpartum check-up and some were unfamiliar with the term. Opinions were mixed on how welcome fathers felt during those visits.

A key source of healthcare information for these fathers is their partners who are active in Facebook moms' groups where information is shared about healthcare and community resources. Participants especially liked the Father's Playbook app and said that having an app like this for dads would help them feel more connected to pregnancy and infant care.

### **Labor and Delivery Nurses**

Participants in these groups regularly and often care for women with high-risk pregnancies. They've learned the nursing skills necessary for this care through training and experience. The sheer number and percentage of high-risk women and babies they see represents a significant challenge to providing comprehensive care. Tyler nurses said approximately 80% of their patients are

high risk and San Antonio nurses said 50% to 75%, depending on the hospital. In two of the three groups, participants described the nurse's role as the eyes and ears of the doctors.

Nurses are typically focused on medical care and have limited opportunities to educate women during their 12-hour shifts. The discharge packet materials that they/their hospitals provide are only geared toward the general population and lack information specific to women with high-risk conditions. In regards to continuity of care after women leave the hospital, nurses cited that limited Medicaid coverage creates a gap. In every group, nurses said that patients' limited education about their conditions contributes to patients not fully grasping the seriousness of health risks or the potential impacts on future pregnancies. Nurses reported that many women believe their health will be fine and their symptoms will subside after having the baby.

All the nurses in every group praised the AWHONN flyer and want to get it in the hands of their patients, especially high-risk women, because it is simple and straightforward information about how to address serious, immediate health concerns. When asked what could improve the transition from the hospital to the community, participants in every group suggested the need for someone to follow up high-risk patients after they go home by phone or, ideally, with a home visit.

#### **Healthcare Providers**

These groups included a variety of healthcare providers, including doctors in family practice, OB/GYN, and internal medicine as well as nurse practitioners and a hospitalist. All of the providers offer some amount of well woman care and consider it an important part of their practices. If they see women who are trying to conceive, providers reported that they educate these patients early on about the ways in which risk factors affect their pregnancies and how to work towards the best outcomes. They see many women with mental health concerns, primarily anxiety and depression, which they may treat within their practices as it is difficult to find a psychiatrist or other accessible mental health support. This reiterates the findings from women who listed mental health as a significant health concern. Providers reported that most women do come to prenatal care and for their postpartum check-ups, but that delayed Medicaid enrollment/approval is the main reason for delayed prenatal care.

Obesity, hypertension, diabetes, and advanced maternal age are the main factors that providers see that put pregnant women at risk. Providers also said that

many patients come to their visits without an awareness of their own health history and risk factors. To manage high-risk health conditions, providers frequently refer patients to maternal-fetal medicine specialists. However, these specialists are not available in many parts of Texas and may or may not accept Medicaid. Also, patients may be required by their insurance companies to visit a primary care provider (PCP) first for referrals, and they may not have an established PCP already. These factors all create barriers. In general, the process of giving referrals, tracking referrals, and finding providers to refer to varies widely and depends on a number of factors — and there are significant barriers that interfere.

Providers typically rely on print educational materials from the American College of Obstetricians and Gynecologists (ACOG) for pregnancy and reproductive health education, but were interested in having access to the print and online materials tested in the focus groups on birth spacing and family planning (such as the . They liked the idea of One Key Question® to routinely ask women of reproductive-age, "Would you like to become pregnant in the next year?" with the goal of proactively addressing root causes of poor birth outcomes. Most of the OB/GYNs believe they are already asking this question in some way, but they do not follow a formal line of questioning and education based on the response.

### Findings from Campaign and Materials Research

### National Campaign Review

SUMA reviewed social marketing campaigns and creative strategies being used in various states, communities, and nationwide to reach the above target audiences with health messages, including on preconception, interconception, reproductive, maternal, and infant health information as well as highly successful campaigns and outreach on other health topics. The most successful campaigns and efforts used a mix of strategies – and all had a strong social media presence – to engage with audiences. This included: photo contests; live conversations on educational topics (usually with a Q&A option) featuring experts in the field; moderated groups and discussions (in English, Spanish, or both); recorded webinars; encouraging and realistic photos representing diverse individuals; art installations; memorable graphics/key shareable images; data in an attractive and relevant format; and information on other resources, such as chats and apps, a text campaign, provider locators, posters and pamphlets to

download, and more. The most robust campaigns were made up of highly-targeted and separately branded sub-campaigns or programs aimed at specific audiences (e.g., providers, young men) or focused in on one key health topics (e.g., birth control, well woman exams). The organizations behind these campaigns were not limited to communications only, but were typically also part of advocacy and/or research and funding efforts, educational outreach and training for professionals and/or community members, and connected to direct service and healthcare providers. Thus, the campaigns and organizations could maintain a presence in the field and stay abreast of best practices and trends.

### **Creative Materials Testing**

SUMA tested creative materials in the focus groups with each of the seven target audiences discussed above in order to assess what content, design, and communications strategies resonate best with different groups (for themselves or their patients, as appropriate). This included web and social media content, brochures, video/audio, and other formats (e.g., a keychain, a charm bracelet, an app for dads).

Overall, women and men across groups – and the providers who serve them – liked bright colors, images that break up text, and summary information with bullet point formats (as opposed to dense text) organized into logical sections/categories. There was a preference also for a Q&A format and/or a social media feed feel. Diverse communities want to see realistic and relatable images; for example, women of color, women of different shapes and sizes, and dads want to see themselves reflected in the images and messages targeted to them. Additionally, there was a strong preference across audiences for online and social media resources. While some audiences requested a print option too (especially healthcare providers), all wanted campaign resources to link to an online presence where they could learn more. Many men and women said that they would click on Facebook posts and ads linked to birth control information. A number of the women participate in Facebook groups as well. While participants also use Instagram, Snapchat, and streaming tv/video/music services, most said that Facebook would be the most appropriate place to receive health-related information.

The current Texas DSHS *Information for Parents of Newborns* booklet was tested in a number of groups as well as a potential alternate design for that resource, the *Bright Futures Pocket Guide*. Additionally, a one-page AWHONN flyer, *Save Your Life: Get Care for These Post-Birth Warning Signs* for high-risk women was tested in

certain groups. While participants appreciated the information included in the DSHS booklet, they suggested it be rearranged into a smaller, more portable, color-coded format such as the *Bright Futures* guide. The AWHONN flyer was extremely popular among both women with high-risk pregnancies and nurses; women said they would post it on their refrigerators and share it with family members in the postpartum period. Additional materials testing findings specific to certain audiences have been noted above in the findings for those groups.

### Findings from Interviews with Coalition Members and Stakeholders

At the time of the interviews, most of the HTMB coalitions were at an early stage of development or were evolving and working to integrate HTMB goals into existing community groups. Most coalitions had not been in existence long enough for members to identify strategic priorities or clear priority populations. The exceptions were Waco and Tarrant County. Participants said DSHS could support coalitions by:

- Providing a central online hub with information about best/promising practices and available state resources, such as the Healthy Texas Women program, and to facilitate connections and communication across coalitions.
- Sponsoring statewide and regional in-person meetings once or twice a year to
  provide information about best practices to coalition members, and offer time
  and space for participants to engage with each other to share lessons learned and
  problem-solve together.
- Organizing quarterly conference calls or online meetings/virtual workgroups to sustain and strengthen connections.
- Offering training to coalitions at various stages of development on basic topics, such as what on what it means to address maternal and child health, coalition building, strategic planning, defining a realistic target audience, collective decision making, and community engagement. Include more advanced training topics as well, such as data collection and analysis, media campaigns and message dissemination, how to drive people to relevant state websites, how to measure the local impact of a state-level campaign, social determinants of health, health disparities, and unconscious bias.

Stakeholders perceived access to care as the biggest barrier to optimal health for mothers and babies. They cited as contributing factors as:

Cost.

- Women's perceptions that their health is not important and a lack of knowledge about risks, danger signs, and available local resources.
- Limited healthcare options for women with high-risk pregnancies.
- A disconnect between providers and patients, including unconscious bias.
- A complicated/inefficient Medicaid eligibility process, and lack of provider awareness about presumptive eligibility.
- C-section delivery for provider convenience.

Stakeholders said DSHS could support them by working to establish a single coordinating body, providing a central online hub for sharing information with other professionals, and sponsoring conferences and workgroups. DSHS can also help to start a conversation among key stakeholders about how to improve coordination and alignment across the many organizations working to decrease maternal and infant mortality, and take the lead to move the state in a positive, collaborative direction.

As a whole, coalition members and stakeholders said the ideal DSHS HTMB campaign should focus on messages related to:

- Self-esteem and empowerment.
- General health and wellness.
- Pregnancy and parenting (e.g., early prenatal care, breastfeeding, safe sleep, postpartum care, and involved fathers).
- Risk signs of high-risk pregnancy and postpartum depression.

Ideally, the campaign would be visual, use easy-to-understand language, and be adaptable to unique local needs and character. The most frequently recommended communication channels were social media and smartphone-friendly information and apps.

#### Recommendations

### **Strategic Efforts**

### Postpartum Depression and Mental Health Care

- Create a partnership with Texas Medical Association or other state or national organizations to identify, share, and promote existing resources for physicians to address postpartum depression as well as depression and anxiety in general, including where they can access continuing medical education on these topics.
- Identify, share, and promote information on how local clinics and community healthcare facilities can promote and expand access to mental health services and care for perinatal women.

#### **Birth Control Education**

◆ Identify access to comprehensive birth control education as a priority for HTMB at the state and coalition level. Create and promote existing resources, such as online information as well as chat/text lines, where community members can get correct, reliable, and nonjudgmental information about birth control from health educators.

### **High-Risk Pregnancies**

- ◆ Partner with organizations like the Nurse-Family Partnership and Healthy Families who already offer in-home care to families to expand their programs to include and prioritize home visits to women postpartum after a high-risk pregnancy.
- ♦ Partner with AWHONN to distribute the *Save Your Life: Get Care for These Post-Birth Warning Signs* flyer to OB/GYNs and labor and delivery nurses who in turn review it with and distribute it to women with a high-risk pregnancy.

#### **Access to Care**

◆ Have HTMB coalitions develop a plan to make sure all women know where they can access affordable high-quality healthcare locally by promoting Federally Qualified Health Centers (FQHCs) and all Title V funded clinics as well as other affordable care in communities across the state.

- Promote links to Bedsider.org and the Women's Health and Family Planning Association sites that offer tools for women to search for affordable healthcare by zip code.
- Partner with HHSC to cross-promote the Healthy Texas Women's program.

#### **Healthcare Communications**

- Identify and promote existing tools to improve communication between patients and healthcare providers.
- Encourage training for providers in public and private clinics as well as in hospitals on unconscious bias.

### **Campaign Format and Content**

### A One-Stop-Shop Website for HTMB

- Create a state-level website that offers easily adaptable tools for locally specific campaigns that inform and support HTMB priority audiences such as links, tools, social media, and specific content for campaign audiences including preconception women and men, interconception women, fathers, women who had a high-risk pregnancy, and providers. The website and campaign should include materials that tested well in the research.
- Include audience-specific content on the topics noted below.

### Overlapping Content for Preconception and Interconception Women

- Self care
- Managing stress and depression
- ♦ Well woman exam 101: what, where, and why
- ♦ How to talk to your doctor
- Questions for your doctor
- Healthy relationships
- ♦ Birth control information, featuring effectiveness and pros and cons of each method (e.g., Bedsider charts and other information that is available to share from Power to Decide)

- ◆ Links to sites that promote provider network information like Bedsider and Women's Health and Family Planning Association of Texas
- Importance of knowing your family medical history
- Avoiding binge drinking, drug use, and cigarettes
- Maintaining a healthy weight through good nutrition and physical activity
- ♦ Links to Healthy Texas Women
- How to navigate insurance
- Tools and content promoting the importance of keeping track of your health history
- Vitamin charts and content on the importance and benefits of vitamins with special emphasis on multivitamins with folic acid

### **Preconception Women**

- ◆ A generic version of the Healthy Waco Women life plan
- ♦ The Healthy Waco Women microsite framework to be adapted for local use.
- ♦ Local resources
- ♦ STD education
- ♦ Body clock and menstrual cycles

### Interconception women

- Postpartum visits: what to expect and how to get the most out of your visit
- Managing diseases during and after pregnancy (e.g., diabetes and hypertension), and where to get help
- Resources to address postpartum depression
- Post-birth high risk warning signs and when to seek care
- The importance of birth spacing
- Self care after the baby's birth
- DSHS branded versions of the *Power Your Family* birth spacing pamphlet and *Birth Control After Baby* booklet.

#### **Fathers**

- ♦ A link to download the Father's Playbook app
- Knowing the signs of postpartum depression and resources
- Managing partner relationship changes as your family grows
- Managing family finances
- Importance of dads attending prenatal and postpartum appointments, and what to expect there
- ♦ Birth spacing information
- ♦ Birth control information
- ♦ How to access health care if you are uninsured
- Importance of annual checkups and preventive care
- Existing links and resources about men's health
- ♦ Information about how to access and promote the University of Texas' Father's Playbook app.

### **Preconception Men**

- ♦ Birth control information
- ♦ STD education and prevention
- Healthy relationships
- Importance of annual checkups and preventive care
- How to access healthcare if you are uninsured
- Link to Young Men's Health website (<a href="https://youngmenshealthsite.org">https://youngmenshealthsite.org</a>)
- Other existing links and resources about men's health

#### **Healthcare Providers and Coalitions**

- ♦ The state-level website should include a portal for providers and coalition members where information can be accessed or materials can be ordered in bulk, including:
  - How to promote/implement One Key Question
  - DSHS branded versions of the *Power Your Family* birth spacing pamphlet and *Birth Control After Baby* booklet.

- A generic version of the Healthy Waco Women life plan.
- One-page resource from Bedsider on birth control effectiveness and pros/cons
- AWHONN post-birth warning signs one-page resource
- ◆ Create and an online social media toolkit that gives coalitions enough content and guidance to make it possible for them to implement social media outreach via Facebook and other platforms, but also allows flexibility so coalitions can add their own local information, address their local areas of focus, and speak in the local language. The toolkit should include:
  - A how-to guide for creating and managing Facebook pages.
  - Guidance on how to brand and use Facebook pages to reach target audiences, as well as measure engagement.
  - A how-to guide for advertising on Facebook and Instagram.
  - Guidance on how to brand and use Facebook ads to reach target audiences, as well as measure engagement and ROI.
  - A how-to guide for creating and managing Facebook groups.
  - Guidance on how to brand and use Facebook groups to reach target audiences, as well as measure engagement.
  - Outreach strategy for contacting the administrators of existing Facebook groups that reach target audiences to promote local services and health education.
  - An editorial calendar that includes images and copy for Facebook posts (for pages and/or groups) and monthly topics of focus to encourage local coalitions to post about the same topics across the state at the same time, but with their own local spin.
  - A framework for the local coalitions to design their own microsite websites, if
    they chose. The sites should target preconception and interconception women
    primarily, and men secondarily. Design elements should include testimonials,
    Twitter feed, Facebook and Instagram accounts, photos and copy that
    support inclusion and diversity, and a clear statement of purpose.

### Methodology

To recruit participants for the focus groups, SUMA researchers created screening tools with questions designed to ensure participants fit the desired profile of study. As recruiting proceeded, SUMA received frequent status updates and addressed any questions about participant qualifications to modify the recruitment strategy as needed, ultimately ensuring the integrity of the research.

Most of the focus groups were comprised of 8 to 10 participants. The sessions were audio-recorded, and the recordings were transcribed verbatim.

During focus groups, researchers do not take exact counts of how many participants respond in a certain way on each line of inquiry, but rather foster a conversation through which participants can speak candidly. Then, as the transcripts of all focus groups are analyzed, trends emerge and qualifiers such as "few" and "most" are assigned to help the reader understand the prominence of each trend.

Please note that the data gathered from the focus groups is qualitative in nature, meaning that it addresses open-ended questions designed to explore matters of "how, why, and what," rather than "how many." Therefore, findings from focus groups should be considered directional rather than statistically definitive.

### Visual Explorer<sup>TM</sup> Icebreaker Activity

In an icebreaker discussion at the beginning of each focus group, the moderator laid out a deck of Visual Explorer™ cards depicting images of a wide variety of people, places, and situations. Participants were asked to browse through the cards and select the one image that best illustrated their overall feelings regarding the topic of their specific focus group



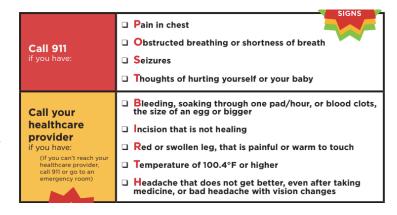
(e.g., feelings about health, pregnancy, effectiveness as a provider). This warm-up exercise introduced the topic of health concerns and set the tone for the rest of the discussions, creating an atmosphere of reflection and open sharing. Participant responses and explanations for their choices are described in each focus group section of the report.

### **Materials Descriptions**

The following health education materials were tested across the focus groups. SUMA researchers purposefully included materials in a variety of styles and formats and discussed style, format, and content with specific groups of participants (as specified below). The findings from these discussions are included throughout the report by focus group composition.

### **AWHONN Flyer**

This 8.5 by 11 inch flyer from the Association of Women's Health, Obstetric, and Neonatal Nurses is entitled *Save Your Life: Get Care for These Post-Birth Warning Signs*. It offers a checklist on complications a woman may face and should watch out for as well as who to contact for help. It also



offers additional detail on why these are important symptoms or concerns in a smaller font below the checklist. It also has guidance on what to tell an emergency or regular healthcare provider and a space to write in the baby's date of birth, your healthcare provider or clinic contact information, and the closest hospital.

This material was tested in focus groups with: women with high-risk pregnancies and nurses.

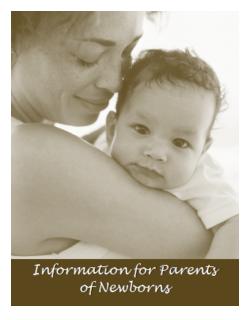
#### It is available here:

https://cdn.ymaws.com/www.awhonn.org/resource/resmgr/pdfs/pbws/pbwssylhandoutenglish.pdf

#### **Texas DSHS Information for Parents of Newborns**

This 8.5 by 11 inch, 28-page booklet produced by the Texas Department of State Health Services (DSHS) contains information that is required to be provided to all mothers by law following the birth of a child. Women typically receive it during their hospital stays.

It has a wealth of information on postpartum and infant care. This includes information on newborn screenings and immunizations, and other guidelines and information about newborns (e.g., safe sleep, dealing with crying, car seats) postpartum mood disorders (depression), how to choose child care providers, and more.

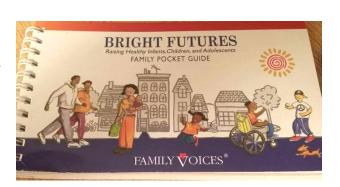


This resource was tested in focus groups with: interconception women, women with high-risk pregnancies, and nurses.

It is available here: https://www.dshs.texas.gov/mch/Parents\_of\_newborn.shtm

### **Bright Futures Pocket Guide**

This resource is a small spiral-bound 4 by 6 inch, 160-page book. It was tested for its look and style as a parenting resource, not for its specific content. The sections are color coded on the right-hand side of each page and it includes bright colors and images.



This resource was tested in focus groups with: interconception women, women with high-risk pregnancies, and nurses.

### **Loving Support Keychain**

This item, a keychain with six colorful credit-card sized plastic cards attached to it, was also only tested for its look and style, not its content. It offers a variety of breastfeeding tips and related images as well as websites to visit or phone number to call for further information.



This resouce was tested in focus groups with: interconception women, women with high-risk pregnancies, and nurses.

### baby gooroo Charm Bracelet

This breastfeeding charm bracelet item was tested in Tyler where the local Healthy Texas Mother Babies coalition is considering using it as a possible intervention for women to incentivize them to attend healthcare visits as well as motivate them to engage in specific health behaviors/activities. For example, women could earn a charm each for attending a nutrition class, breastfeeding class, and an infant care class. The format tested and shown below is available through the store at <a href="https://babygooroo.com">https://babygooroo.com</a> for \$12.50 each including all six charms.

This resource was tested in focus groups with: interconception women and women with high-risk pregnancies in Tyler only.

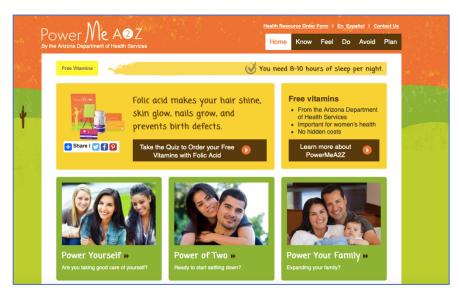






#### PowerMeA2Z Website

The PowerMeA2Zwebsite is part of a larger preconception and interconception health campaign by the Arizona Department of Health Services and based on social marketing research and direction by SUMA. It is designed to educate women of all ages and their partners – whether or not they are planning to conceive – about health, wellness, and the importance and value of folic acid vitamin consumption.



The campaign website includes interconception and preconception health topics as well as distributes free vitamins with folic acid. It has information, quizzes, resources to download or order, and the opportunity to request a Power Pack with resources and free vitamins.

This resource was tested in the focus groups with: preconception women, interconception women, and healthcare providers.

It can be accessed here: <a href="https://www.powermea2z.org">https://www.powermea2z.org</a>

### **Power Your Family Pamphlet**

This approximately 8.5 by 4 inch pamphlet (standard size) from Arizona's PowerMeA2Z's campaign is designed to help women and their partners make educated decisions about birth spacing. It details the health reasons behind Centers for Disease Central and Prevention (CDC) guidelines of waiting 2 years following a birth to try to conceive again and offers a set of questions related to health, lifestyle, family dynamics, and how having a new baby would affect every member of the family.

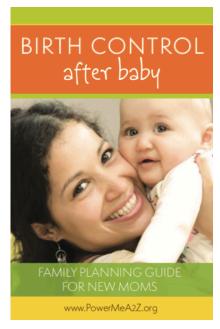


This resource was tested in the focus groups with: interconception women, fathers of young children, and healthcare providers.

It is available in English at: <a href="https://www.powermea2z.org/wp-content/uploads/SUMA\_Arizona-BabyPlanning-Brochure-proof-061014.pdf">https://www.powermea2z.org/wp-content/uploads/SUMA\_Arizona-BabyPlanning-Brochure-proof-061014.pdf</a>

And in Spanish at: <a href="https://www.powermea2z.org/wp-content/uploads/SUMA\_Arizona-BabyPlanning-Brochure-Spanish-061014.pdf">https://www.powermea2z.org/wp-content/uploads/SUMA\_Arizona-BabyPlanning-Brochure-Spanish-061014.pdf</a>

### Birth Control After Baby Booklet



This approximately 7 by 9 inch, 44-page booklet from the *PowerMeA2Z* initiative details a variety of birth control options with quick facts, including a comprehensive chart that compares average cost, duration, and effectiveness of each one. It is colorful and full of pictures of women and families.

This resource was tested in the focus groups with interconception women.

It is available in English at:

https://www.powermea2z.org/wp-content/uploads/03-Birth-Control-After-Baby-English-All.pdf

And in Spanish at: <a href="https://www.powermea2z.org/wp-content/uploads/BCAB-SP-web.pdf">https://www.powermea2z.org/wp-content/uploads/BCAB-SP-web.pdf</a>

### PowerMeA2Z Life Planning Tool

This life planning tool includes information on a variety of health topics specific to women, including birth control, vitamins and nutrition, stress, healthy relationships, exercise, and more.

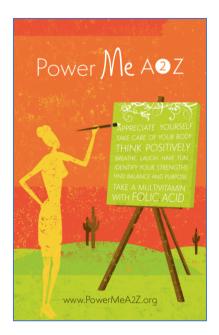
It was tested in the focus groups with preconception women.

Life planning tool (English):

https://www.powermea2z.org/wp-content/uploads/Life-Plan-Spreads-Approved-020813.pdf

Life planning tool (Spanish):

https://www.powermea2z.org/wp-content/uploads/SUMA\_LifePlan-Span1.pdf



#### **Bedsider Website**

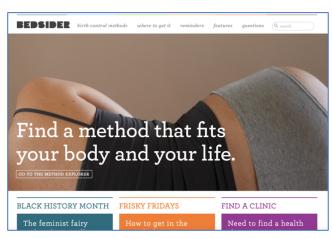
This interactive website is focused on providing comprehensive birth control information to everyone of reproductive age as well as education, answers to common

questions, and practical resources. It features engaging photos of a variety of individuals, up-to-date information, resources, and products to purchase with catchy messages.

This resource was tested in focus groups with: preconception women, preconception men, and fathers of young children.

It is available at:

https://www.bedsider.org

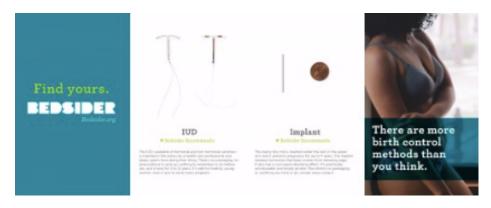


#### **Bedsider Birth Control Pamphlets**

This approximately 8.5 by 4 inch pamphlet (standard size) from the Bedsider campaign designed for men or women and includes professional photographs and straightforward information on every type of birth control available. A second pamphlet from the same campaign was also tested.

This resource was tested in focus groups with preconception men and fathers of young children.

It is available at: <a href="https://shop.powertodecide.org/educational-materials/catalogs-and-brochures/visual-guide.html">https://shop.powertodecide.org/educational-materials/catalogs-and-brochures/visual-guide.html</a>



### Father's Playbook App

This resource from the University of Texas at Austin Dell Medical School is aimed specifically at men/expectant fathers during the prenatal and postpartum periods. It provides education and tools about pregnancy (i.e., biological development as well as symptoms their partner might experience) as well as information on infant development and care. It also focuses on the role men can play at each stage. It includes financial advice as well as general information on preparing for a baby. The design of the app is based on of a website by Texas Safe Babies (See: <a href="http://menspregnancyplaybook.com">http://menspregnancyplaybook.com</a>).

This resource was tested in the focus groups with men with young children.

This resource was piloted with a release in the Android store, but is still under development, so no link is currently available.

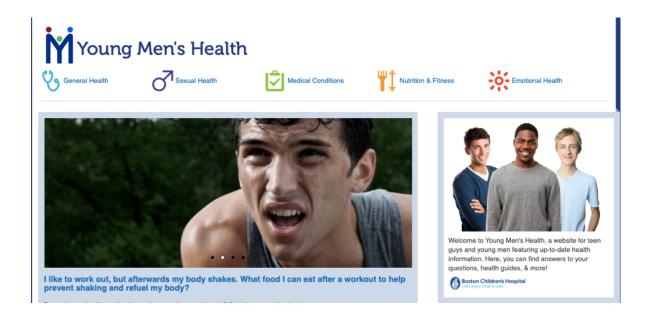


### Young Men's Health Site

This website from the Division of Adolescent and Young Adult Medicine at Boston Children's Hospital includes comprehensive health information for young men – including general health, sexual health, mental health, fitness, and health conditions. It includes a lengthy list of guides and resources as well as quizzes and information for parents of 13-22 year old young men.

This resource was tested in the focus groups with preconception men.

It is available at: <a href="https://youngmenshealthsite.org">https://youngmenshealthsite.org</a>



### Additional Campaign Websites, Ads, and Life Planning Tools

Participants in the focus groups with preconception women reviewed the overall websites for the following campaigns as well as complementary life planning tools and ads aimed at women as noted:

- Healthy Waco Women (website and life planning tool)
- Someday Starts Now (life planning tool and ads)
- ♦ Show Your Love (website only)
- ♦ PowerMeA2Z (see information above)

Each campaign is focused on a variety of women's health/preconception health and wellness behaviors, information and guidance on health topics (e.g., well woman exams, birth control, healthy relationships, stress, vitamins and nutrition, exercise, and more). Each campaign includes a specific subset of topics in line with its priority audience(s) and objectives.

Similarly, the complementary life planning booklets include practical health information and guidance on a variety of key topics. All of the booklets tested are aimed specifically at preconception women:

### Healthy Waco Women

This targeted preconception public health campaign focuses on the importance of annual well woman exams and preventative care. In addition to providing basic information about what questions woman may want to ask and what to expect during the exam, the website lists and maps the location of local providers



offering free or low-cost services. It also includes a life planning tool for women (as pictured). This campaign is available at: <a href="https://healthywacowomen.org">https://healthywacowomen.org</a>

### Someday Starts Now

Someday Starts Now is a public awareness campaign used by the Texas Department of State Health Services' Healthy Texas Mothers Babies program. The campaign comprises

printed materials and a bilingual website, including tools for providers in the healthcare and community settings, life and birth planning tools, videos on the importance of breastfeeding, partner involvement, and preconception health (especially as it is connected to future pregnancies) as well as information for men and women of childbearing age for before, during, and between pregnancies.

Two additional items from the Someday Starts Now campaign were also tested in the preconception women focus groups.

- A 30-second radio ad
- ♦ A 15-second video ad

An example of a video ad tested is available at: https://www.youtube.com/watch?v=X2x2utm0EEA

The campaign is no longer active, but information is available at: <a href="https://dshs.texas.gov/healthytexasbabies/Someday-Starts-Now.doc">https://dshs.texas.gov/healthytexasbabies/Someday-Starts-Now.doc</a>



### Show Your Love

This national preconception health campaign is aimed at young adult and provides guidance, information, and motivation about healthy lifestyle choices, including preconception health behaviors. It includes a variety of tools and resources.

Available at: <a href="http://showyourlovetoday.com/">http://showyourlovetoday.com/</a>



### **Preconception Women**

### **Participants**

During the fall of 2018, SUMA conducted five focus groups with young women between 18 and 25 years of age who do not have children. Table 1 provides additional details on participants.

Table 1: Participants (N = 39)

Location	Participants
Amarillo	10
San Antonio	8
Tyler	8
Beaumont (African American)	5
Laredo (Spanish)	8

### **Lines of Inquiry**

The interview guide for the five focus groups with nurses is included in the Appendix. The lines of inquiry included:

- Discussion about current life priorities and health concerns
- Experiences in accessing healthcare, including willingness to access care as well as specific barriers
- ♦ Knowledge and experience about the value of preventative care, specifically well woman exams
- ♦ Knowledge and experience using and obtaining information about birth control
- ♦ Sources of health information, including formal and informal channels as well as media/social media habits
- ♦ A review of a wide variety of preconception and young women's health resources (tools, videos, websites, etc.) as well as discussion of their appeal

### **Detailed Findings**

### Where Preconception Women Are in Life

In an opening exercise, the moderator asked participants to choose a card with an image that represents where they are in their lives. Some women shared that they feel stressed about transitions, such as leaving home for the first time, and generally feel busy and that their lives are hectic. Other women spoke about striving to meet their goals, like performing well in their classes. A few said they are currently focused on having fun.

I picked the picture of a young child's hands holding a bird. What that represents to me, what I thought when I saw, it is just kind of – I'm also in college right now. I'm trying to be a teacher, so, to me, it kind of represents me holding out my hand to nourish and help people coming towards me. – San Antonio

It looks like a dude that's jumping off of something really high. He's about to skydive into the water or something. I don't know. Basically, I like this one because it explains how crazy my life is with school and everything going on, I just feel like I'm always jumping out of the sky into something new. It's crazy. It's horrible. – Tyler

I picked this one [of a dancer] just because she just looks like she's having fun and enjoying their life [sic]. – Laredo

### **Priority Health Concerns**

When asked what their top of mind health concerns were, women listed the following:

- STDs and STD prevention
- Mental health, especially depression and anxiety
- Birth control fear of having it "taken away," having it covered by insurance
- Pregnancy
- Abortion services
- Obesity
- Healthy eating
- Physical/annual checkups
- Pap smears

- Healthcare costs and access
- Drug and alcohol addictions and overdoses
- Not being able to have children
- HPV
- Abuse/domestic violence
- Cancer breast, skin
- HIV
- Not knowing where to go for healthcare
- Ability to qualify for/afford insurance

STDs and STD testing were top concerns among the participants. Many young women said that mental health issues, especially depression and anxiety, are also top of mind health concerns. Participants listed dealing with debt/finances, moving away from home, college pressures, jobs, interpersonal relationships, and dating as factors that contribute to their depression and/or anxiety. A few women brought up how stigma around mental health can make it difficult to address those issues, especially at work.

Personally, for me, because I'm the only child, when I went off to school this was my first time ever being away from my parents on my own. My freshman year in college I went through a deep state of depression because I never was on my own before. So, it's me trying to find out who I truly am and not who my parents have raised me to be, but find my own, be my own person and not be this person that my parents raised me to be. Don't get me wrong, I still have my foundation of how they raised me, but, still, I have to make a name for myself. – Beaumont

Men, social life like having to deal with going out or working or paying bills and like that. It puts you in depression, it does. – Beaumont

It's kind of hard to address some of those concerns without people giving judgment. If you're at work... it's hard to say I need a sick day because of so-and-so, my anxiety or whatever, and they don't take you seriously. – San Antonio

Well woman exams came up organically in two cities. A couple of participants in those cities brought up that women their age are not getting their annual well woman exams for a variety of reasons, including not knowing where to go for an exam, what an exam entails, and that they need one every year.

A lot of girls aren't getting their annual Paps and stuff...Or not knowing that you need it. Or not knowing where to go. What it is. – San Antonio

Recently, I had to go get my well woman exam. I learned that not a lot of women go and get their well women exam, and we're supposed to do that. – Tyler

## **Barriers to Healthcare**

When asked what may prevent them from addressing their health concerns, many women brought up not being able to afford doctors' visits, because they either did not have health insurance, or their insurance did not significantly offset the cost of care. Several women also expressed confusion or uncertainty about navigating the healthcare system to find doctors that can help them and that they can afford or are covered by their insurance. Some women said that their busy work and school schedules can be a barrier that prevents them from getting checkups as well.

Participant 1: I'm a college student, so most college students actually don't have health insurance because they're working part time,...most employers want their employees to be full time to actually be covered.

Participant 2: I have a lot of friends who don't have insurance. They can't go to the doctor without having to pay over \$100.

-San Antonio

Personally, my insurance sucks. It doesn't cover anything mental health-related. I was going to therapy but I'm not anymore because I just can't afford it, which is a shame because I have issues. – Tyler

I don't have any insurance in my job. I'm a caregiver for Visiting Angels. They offer it, but they take so much out of your check. You get paid weekly. It would leave me nothing. ...I've gone to Planned Parenthood a couple of times just to get tests, different things like that done, but with the contraceptions [sic] and things like that, you do have to pay for it out of pocket. I don't have it. – Tyler

I never have time to do anything, basically, for myself, other than 7 p.m., but everything's closed. – Amarillo

A few participants brought up that they would not feel comfortable going to male doctors; their impression is that most doctors are male, so they assumed it would be difficult to find a female doctor.

I would say that a lot of insurance are picky about your doctor, too. They pick your doctor for you...we could only find male gynecologist. I wasn't comfortable with that. So, I just haven't gone in for a well woman check because I'd rather just not. – Tyler

# Searching for Answers, Taking Action

Participants were asked what they do to address their health concerns. The most common answer was to turn to Google. Women said they would search for answers to questions such as when to take Plan B, how many pregnancy tests to take to confirm a pregnancy, and why their menstrual cycle was starting late. Most women could not recall a specific website they used to answer health questions aside from WebMD, but rather that they click on whatever sites their Google search returns. Some women agreed that they look at multiple websites to see if there is a consensus about a topic, but most women did not have a specific trusted online source that they return to for health information.

Participant 1: Yeah, I just type it in Google.

Participant 2: Whatever pops up on Google.

Participant 3: Then you just click whatever.

Participant 4: I look at more than one source for the information...because I have to make sure they say the same thing.

-Beaumont

Many women said they talk to their mothers about their health concerns too. Some said they speak to female family members, such as aunts and sisters, or their friends. A few have a trusted doctor they feel they could talk to about concerns. A few said they do not discuss their health concerns with anyone. Many women also talk to their mothers about their reproductive health, while some said they would prefer to talk to their friends instead about intimate detail of their sexual health.

My mom is the first person I call. I'm like, "Yo, what's going on with that?" If you go to your doctor and think it's — I have a general practitioner, so they're just there if you get sick, pretty much. If I'm like, "I'm having anxiety," or, "I think there might be something wrong down there," they're referring you to all these places, and I don't know if these places are covered by my insurance. It's kind of like a dead end either way.

#### -San Antonio

I would say probably my best friend on that because she can't really say much because she's been through a lot of the same things. She's not going to judge me. – Laredo

For sexual health concerns, women said they get on birth control, use condoms, get tested for STDs, and have one sexual partner at a time.

Personally, I got on birth control just for protecting myself. At first, it was an up in the air thing because birth control works different on different women...I knew personally that I needed to, so I did that...STDs, I get tested every three months when I go home. Just self-checks, you want to make sure that you're aware. Especially any time you switch from a different sex partner, you want to get yourself checked out because especially nowadays, boys are dirty. They don't care. Especially our age group, they don't care.

—Beaumont

To address mental health issues such as depression, some women said they turn to self care strategies, such as yoga, church, spending time with friends, or listening to music.

### Access to Care

Half of the focus group participants had health insurance and half did not. While many women were not able to afford insurance, even those with insurance were worried about out-of-pocket expenses. Some of the women were aware of places in their communities where they could receive low-cost care, others were not. While these women spoke of valuing these resources, some pointed out that they thought the services were not always well known in their communities. This finding was reinforced by the fact that many women at the end of the focus groups said they learned about services that night in the discussion that they had never heard of before. Out of five focus groups across the state, only one participant was familiar with the Texas Healthy Women's program, which suggests that the current promotion of that program is not widely reaching its target audience.

...at TJC [Tyler Junior College]. If you go there, you automatically can go to their health clinic and different things and not pay for it because it's included in your tuition, but people don't even know that it's an option. – Tyler

There's also programs for women. I'm in the Texas Healthy Women, I think it's called, and I didn't know about that. You can get so many exams done, like blood work and all of that, and it's nothing out of pocket. A lot of people don't know all of this. –Tyler

The participants in two different communities who said Planned Parenthood was a trusted source of healthcare for them also described how vocal resistance to the organization can potentially negatively impact their ability to access those clinics.

I go to Planned Parenthood. Some people really hate it. They have a bad connotation about it, but they're very helpful. If you bring your check stubs, you tell them you're in school, they'll calculate a discount for you. They'll help you get birth control or whatever

you need. Then they do – for \$15, they'll do your testing for AIDS and things. Then, for an extra \$15, they'll do for all the different diseases to see and make sure. They're really helpful about that. They get it done fast. You can just walk in. It's a little odd because there's people outside. They're praying and they're making noise. They're not very happy. – Tyler

Participant: There's a place. I don't have insurance or anything like that. It gets expensive. There's a place called Haven where you can apply for stuff. Then they'll pay for it.

Moderator: Let me see how many hands have heard of Haven? Nine [of ten].

-Amarillo

If I do go to the doctor it'll be clinics, but I have to pay out of pocket, so I have to pay for the consultation, then my medication, so it's just like so expensive. I'd rather not seek help because that just discourages me because it's so expensive. – San Antonio

# **Experiences with Healthcare Providers**

Women had gone to a health professional in the past year for the following reasons:

- STD testing
- Pregnancy scares
- Birth control
- Feeling sick
- Flu
- Annual well woman exam
- Anxiety and depression

- UTI
- Kidney infection (hospitalization)
- HPV vaccine
- Flu shot
- Allergies
- To receive ADHD medication

Overall, the only preventative care participants receive is STD testing, birth control consultations, and, for some, a well woman exam. Some women said they only go to the doctor if they are acutely ill or need to renew prescriptions, such as birth control. Generally, as mentioned above, this is due to the costs or not knowing about alternative options, such as clinics.

When asked what they talk about with their doctors when they do go in for care, several said that their appointments feel rushed and they do not have adequate time to discuss topics at any length. Some women said they have a doctor that they like, and feel comfortable answering when the doctors ask questions about their sexual health.

Some women are still going to their pediatrician at this point in their lives, several of those mentioned that they have had a long-term relationship with this doctor and feel comfortable going to them. Conversations in San Antonio revealed that all participants were concerned that doctors do not take them seriously, perhaps because of their age or gender.

Participant 1: It's just a really brisk, "Are you sexually active?" "Yes." "Are you being safe?" "Yes." "See you next year."

Participant 2: They rely on you to know what to talk about, but, no, it's like you feel when you get in there, especially if you're going in there for anxiety or something, you feel so overpowered.

Participant 3: It does feel like because we're a younger group and we go to the doctors, they don't take us seriously.

-San Antonio

### Well Woman Exams

When moderators asked participants what they think of when they hear the phrase "well woman exam," most women said they think of a Pap smear and vaginal exam. Some said they also think of STD testing and breast cancer screening as being a part of an annual well woman exam. There were a few women in each group who were unaware of what a well woman exam is. In San Antonio, several participants had not heard of a "well woman exam" and were generally uneducated about what they entail.

Participant 1: I still haven't gone. I don't even know what it is.

Participant 2: You don't know what a Pap smear is?

Participant 1: No one ever explained it to me.

- San Antonio

Some participants had had a well woman exam in the past year, while others said they had had one in the past, but not this year. When asked why they had not, participants said that they do not have the money to go to the doctor, that they feel well, that they would not want to receive bad news from the doctor, and that they are scared that the exam itself is painful. In Tyler, participants also reported a lack of transportation to the appointment as a barrier to preventative care.

There was general concern among participants that the Pap smear and/or vaginal exams are painful or uncomfortable because it entails someone touching and looking at

their genitals. This concern was more prevalent among women who had not yet had a well woman exam. Additionally, there was some confusion in the groups about at what age well woman exams were to start (18 years versus 21 years versus when a woman becomes sexually active) and how often Pap smears are required (every year versus every 3 years).

Participant 1: I just feel uncomfortable. That thing going in there and everything happening in there and just taking it out. Just the thought of it, I'm scared of it.

Participant 2: I've had a pelvic exam, but not the whole women's exam, but I don't know. It's just a little nerve-wracking because it's just awkward.

-Tyler

Participant 1: I'm scared. [Several participants agree.]

Participant 2: Yeah, because I'm not – I don't know. I don't feel like I would be comfortable, and I'm just scared because what if it really does hurt?

- Beaumont

Women who had been to a well woman exam said they were weighed, had their blood pressure taken, had their breasts checked, were asked if their vaccinations were up to date, and were given a vaginal exam and/or Pap smear. These women were able to easily describe the various steps in the exam.

When moderators asked participants where they could go to schedule a well woman exam in their community, some women had a gynecologist they could go to or said they would try to schedule with their mom's gynecologist. Several said they would not know where to go. Most women in Amarillo said they could call The Haven clinic and book an appointment for two months out since they have a waitlist, or do a walk-in appointment. In San Antonio, none of the women were confident about where they could go. A few who did not know off the top of their head where they could go for a well woman examine stipulated that they would try to look for a female doctor to conduct the exam, and to find a place that was affordable.

Participants were asked what would make them more likely to go to their annual well woman exams. The top-of-mind response from women was, again, "How much will it cost?" Several women agreed that they would like to understand what they can expect from the exam before going to the doctor. Women also said they would like to know where to go, if it was covered by their insurance, how long the appointment would be so they could schedule it around work and/or school, and if they would be seen by a doctor or a nurse. Participants agreed that, if they were informed about these factors, it

would help them make the choice to go get a well woman exam. One woman shared that reading testimonials from other women who had gone to these exams helped her decide to go to hers.

I want to know from as soon as the doctor walks into my room to when she walks out my room, the whole process, so I can be mentally prepared; won't nothing catch me off guard.

- Beaumont

Something I would want, too, because a lot of girls are really scared to get exams like that — it's uncomfortable — especially young girls. I have a cousin who is my age and hasn't ever had a Pap smear, which is ridiculous and scary. There were reviews of young girls who go there and like, "Hey, it's not that bad. They make you feel really comfortable." Some positives reviews definitely helped me go. — San Antonio

## **One Key Question**

The One Key Question® initiative encourages all primary care health teams to routinely ask women of reproductive age, "Would you like to become pregnant in the next year?" with the goal of proactively addressing the root causes of poor birth outcomes and disparities in maternal and infant health. Women are then offered follow-up preventive reproductive health services specific to their needs. This initiative is being used in some locations around Texas, so participants were asked about it to determine their reaction and preferences.

When moderators asked how they would feel if their doctor asked them the One Key Question noted above, the answers varied. Women in Beaumont and a few in San Antonio said they would feel anxious and wonder if the doctor is about to tell them that they are pregnant. Women in other locations felt more positively about the question and said hearing it would help them assess where they are in life, or they said that it makes sense for a medical professional who is also asking about birth control and other aspects of reproductive health to ask that question. Some participants had been asked the One Key Question by doctors in the past and said that, while the doctor did not explain why they were asking the question, they assumed it was related to their overall health and did not mind being asked.

Yeah, I would be like, "Do you see something?" Like, "What's up? Are you trying to tell me something? What's going on?" – Beaumont

"Are you having unprotected sex?" I was like, "Yeah." They were like, "Are you trying to get pregnant?" I was like, "No." They were like – it made me think I need to get my life together, I guess. I need to start having safe sex. – Amarillo

I feel like if [the doctors are] asking [the One Key Question], it's for a reason, depending on what you're going for. There's birth controls that will last five years. There's birth control you can get everything three months. It could be for different reason. – Laredo

## **Birth Control**

When asked how easy or hard it is to talk to their doctor about birth control, participants were split. Some women felt comfortable talking with their doctor about birth control, while others did not, saying they did not have a relationship with the doctor they saw, or felt like their doctors were pushing birth control or certain methods on them without having a true conversation about their needs or desires.

I feel like sometimes physicians can get rude with it. They try not to, and they'll try to hide it, but they'll prescribe you a certain one that they think is right for you, but for you and if you're not really knowledgeable it and you go home and read and look it up it's not really like what you were looking into. There's different types of birth controls out there and there's some with more hormones than others, and they'll say — like if I wanted to stop my period completely, but the gynecologist says, "No, you need one with less hormones." It's opinion versus knowledge. — San Antonio

Based on conversations in the focus groups, it was apparent that these young women were not well educated about birth control. This lack of knowledge and concerns about side effects impact use. Women in each community had questions about the mechanics and side effects of various birth control methods. A notable number of women expressed a lack of trust in regards to their healthcare providers and birth control. Some said they believed their provider had an ulterior motive, which included making money or having free access. They did not feel like what was in their best interest was being offered to them. The participants did not talk about a trusted "go-to" source for birth control information.

Participant 1: Don't they get paid to prescribe certain medications more than others?

Participant 2: *Probably*.

Participant 2: It feels shady because they push it on you and then it's, like you said, even if you're happy with what you get, they have an agenda or something to show you options.

Many had questions which included concerns about the possible negative impact on fertility, weight gain, bleeding, and reliability. Some reported bad side effects like excessive bleeding. Participants wondered if it was possible for a woman uses birth control for "too long" and become infertile, and if methods that cause women to stop menstruating are healthy. In Amarillo, most women in the group had heard that using birth control can make it harder to have a baby later in life.

Participant 1: A lot of people think, if you're on [birth control], it could be unhealthy.

It's kind of scary because I've been on birth control since I was 16. I kind of want to get off of it soon. I'm not saying I want to have a baby soon, but I don't necessarily think that birth control can always be good. I've heard a lot of negative things about it. It's kind of scary.

Participant 2: For example, my sister-in-law, she was on birth control. She had a kid first. Then she got on birth control. She was on it for four years. When she got off of it, she tried to have kids for two years, and she couldn't...it just made her – I guess you're infertile. I don't know.

-Amarillo

I used to get the shot. There was a lot of side effects and things that you don't know about. I guess you may get told – obviously, you're going to be told about them right before, but it would be nice to know that. When you're looking at all this right here together, you're like "Wow, this looks like a good deal," but then you, later on, look at it. –Tyler

As mentioned, several women felt pressured by their healthcare providers to get on birth control or use a certain method, but the women generally did not have a firm grasp on which option would work best for them. Participants said that doctors do offer a variety of birth control options, but the women felt frustrated and concerned about their choices. Some of the women in the groups reported that they are not currently on birth control because they still have unanswered questions about how different methods will affect their bodies.

My family recently got a new doctor back in Dallas, so went there right before coming back here at the end of summer. I told her I love being on the shot. I don't have my periods. I don't get cramps. I don't get moody. It's perfect. It's great for me. She was like, "Oh, you should look into the IUDs and the implants." I'm like, "No, I just told you I love this. Why?" – San Antonio

When I went to Planned Parenthood, I said something about the pills for birth control, just so it's something I take every day and if I don't want to keep taking it, but she is just pushing and pushing to get the implant in my arm. ... "We can give you a free one." They kept egging it on. I was like, "No, thank you." It's good that they have so many alternatives, but it's kind of hard because it's something that's stopping a natural thing that's happening with your body. Obviously, there's going to be something, but it is kind of scary not knowing the long-term effects of it. I haven't started anything just because I'm really still trying to figure out if I really want to take that chance. – Tyler

## **Other Sources of Health Information**

Women said they get information about staying healthy from family, friends, health classes in school, and online through Google, YouTube, or social media platforms. Pinterest, YouTube, and Instagram were mentioned as places that these young women see healthy recipes and workout routines online. As mentioned previously, several women said they will Google their symptoms and possibly check WebMD if they are feeling unwell. A few women remembered seeing women's health-related commercials recently, which were related to medications or birth control methods, such as Nexplanon.

YouTube. I like to cook, so I always look up recipes — like healthy recipes and workout routines. That's what I do. – San Antonio

[When I go to Google], it's straight to the point, like, "Why is my cycle late?" or something like that. "Why am I having this issue?" or something like that. – Beaumont

I've been seeing, "Armor up." That Nexplanon, the birth control. I remember that, "Armor up." That's what it says, "Armor up." – Dallas

### Online and Traditional Media Use

It was clear from these focus groups that traditional advertising campaigns that rely on network ads or radio ads will not reach this generation. Participants confirmed that they do not watch traditional cable television or standard networks or listen to traditional radio.

Women reported using the social media and streaming services listed below for entertainment.

#### Social Media

Many participants said that they use Facebook, Twitter, Instagram, and Snapchat. A few said they use Pinterest and Reddit. The women agreed that social media is the best way to reach them with messages, since that is where they spend a significant amount of their time. One participant mentioned that she saw an ad about STD testing in Snapchat. A few also said they saw ads on Tinder for STD testing. One woman also said she saw ads about LGBTQ health on Instagram.

<u>Music</u>: Many women listen to online music streaming services. The most popular are Spotify and Pandora. Others that were mentioned include Apple Music, Musi, and SoundCloud. Women were split on whether they use the free versions of the services that play ads or the paid versions with no ads. Some participants said they listen to local radio stations, mostly in the car.

<u>Video/TV</u>: Most women said they do not watch cable TV, but instead use streaming services such as Netflix, Hulu, YouTube, and Amazon Prime. A few said they watch these streaming services through their Roku or Amazon Fire Stick. Only a few women said they have cable in their homes.

<u>Apps</u>: Some women reported that they use health-related apps as well, including NikePlus and MyFitnessPal. Several participants use period tracker apps such as Flo, Period Tracker, Life, My Days, and Spot On. A few also had either Fitbits or smart watches that they use to monitor their health.

# **Materials Testing**

Participants had the opportunity to review and give feedback on multiple health promotion and educational resources, discussing how appealing and engaging each one was for women like themselves. More information on the individual resources can be found in the Materials Descriptions section earlier in the report.

## Someday Starts Now Ads

Two items from the Someday Starts Now campaign were tested with focus group participants.

<u>30-Second Radio Ad</u>: Women generally did not think this ad was for them because it sounded like an ad for women planning to have a child soon. They agreed that the message of the ad was that women who want children should start engaging in healthy

behaviors, but that message does not resonate with where they are in their lives currently. Some participants said the voiceover sounded too rehearsed or planned. Others said they would tune it out if it was a commercial on a streaming music service or radio station.

15-Second Video Ad: Women reacted more positively to the video ad than to the radio ad. While they liked seeing a diverse group of people in various scenarios, they said the ad seemed to be for older people who were planning to have a baby because of the use of baby due dates. This item did not resonate with many women in this age group who are not planning to have a baby at this time. Women felt that the message was the same as the radio ad, to take care of your body in case you have a baby someday. While a few said that was thought provoking, most said they would prefer ads that focus on their health now rather than to be healthy for future pregnancy.

I would say being healthy shouldn't just have to be like, "Hey, you're going to have a baby." You shouldn't be just healthy for this baby. You should be healthy for yourself. -Laredo

It just made me want to be my most healthy, so I could – whenever I'm ready for that, I can do that. – Dallas

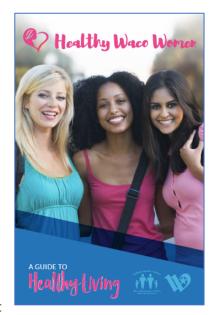
I like how they had all different types of people, all different shapes and sizes, and then also just different ethnicities. You kind of feel like you see yourself in something because sometimes I don't ever see myself. I can't ever picture myself in a situation or something because I'll look at things. I'll be watching TV all day, or I'll be online, and I don't see anyone that looks anything like me, not just body wise but skin wise, everything. – Tyler

## Life Planning Booklets

Participants were handed three printed life planning tools from the following campaigns and given five minutes to read over and review them:

- Healthy Waco Women
- PowerMeA2Z
- Someday Starts Now

Healthy Waco Women Life Plan: For most of the women, this was their favorite of the three life plan options. They preferred the overall colors and design. The centerfold birth control chart was a popular feature among participants, since it gives in-depth information about the effectiveness and potential risks of various methods. Some women remarked that they did not know there were so many forms of birth control before they saw this chart. Others said they liked that the titles throughout the resource are in the form of questions, such as, "Are You Getting Enough Sleep?" Women also liked the local resources in the back, saying they would like a similar list for their areas. Women said they learned about the three-year interval for getting a Pap smear, and what to expect at a well woman exam from the booklet.



The birth control [chart], it shows you the different forms and the statistics on women getting pregnant, so I like that, and then the options and where to get it and the side effects. I like that it tells you what's what, and then it gives you information like what could happen and the effectiveness. – Beaumont

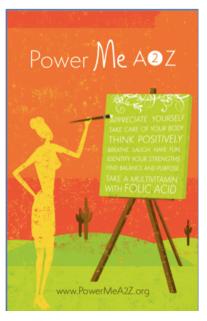
Participant 1: I liked the resource list with that.

Participant 2: I wish this was local.

Participant 3: Yeah, that's exactly what I said. That was super nice, except it's not local.

-Tyler

<u>PowerMeA2Z Life Plan</u>: The topics covered in this resource resonated with participants, including healthy relationships, menstruation, and stress. Women in multiple groups said they liked the "true or false" statements. Some liked the bright color scheme, while others did not. The vitamin chart was a popular feature in this booklet, which includes information on which foods contain which vitamins and how they support women's health.



The vitamins, I think it was cool because it told different – if you eat certain stuff, what it helps for. I thought that was pretty cool. – Amarillo

We go through a lot of things, and it's like you don't really have that person to talk to because they might not take you serious. For them to say, "Stressed out, explain it, your signs of stress, how to relax." I feel like that's a good page to have. – Beaumont

## **Someday Starts Now Life Planning Tool:**

Women in the groups said that this tool was thought provoking, and made them consider questions about their future they had not yet answered such as, "How many kids do you want?" Yet overall, it was the least compelling to women of the three life plans tested. Some women did not see themselves filling out the life plan questionnaire, saying that it was too long and felt that some of the questions did not pertain to them. Some women said they had



questions about how the tool was supposed to be used, in that they wondered how it would be valuable to them after they went through the exercise of filling it out. Some wished it would have provided guidance for what to do for their health given their answers.

Several participants saw the tool as only being useful for women who were planning to have children, and not geared for women like themselves in their stage of life.

It's kind of funny because the moment you gave me this one, I got this one at the doctor's office, and it's in the trash can. I'm not going to lie because that's just not me. Not doing that right now...It started with "life planning tool." I'm not trying to plan kids right now. — Tyler

I think somebody who just wants to be single for the foreseeable future, would I need to bother looking at this? – Tyler

When asked if they would like to receive information from these tools online, women agreed that excerpts of the information (e.g., the vitamin and birth control charts) would catch their eye on social media networks like Facebook and Instagram. Some women did say that they would still like to have the paper version of the information that they could pick up and easily reference, and that could be a "starting place" for finding more reliable information about specific topics online. Women said they would expect to receive booklets like these from a doctor or through their college.

## **Text Message Campaign**

Moderators also presented the idea and examples of a text messaging campaign that would include reminders and messages about where to get free birth control and reducing stress through exercise. Several women responded favorably to the idea of signing up to receive texts about women's health. In addition to the sample messages/topics noted above, participants also said they would want to receive messages about mental health and eating healthier. Several participants agreed that receiving texts twice a month would be a good frequency. Participants stipulated that they would want to opt-in to such a service, stating that if they received messages like these without having signed up for them, they would not trust them and regard them as a potential scam.

### Websites

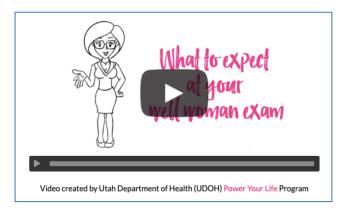
In addition to the tools and options described above, moderators also showed participants websites from the following campaign for review and feedback.

<u>HealthyWacoWomen.org</u>: As mentioned in the Materials Descriptions section, this website and campaign is focused on well woman visits as a key health behavior. Women agreed that having a website that would allow them to find well woman exam providers in their community would be helpful for them and their friends, and that they would be likely to share that site. Some women in every group made note of the information on Pap smears being required every three years and that well woman exams are usually free, saying that that was new information to them.



I really like the information that it tells about the Pap smear. You need it every three years, not every year, because women probably do stress about, "I need to go get the exam done every year." Instead of just doing it every three years, they're getting it done every year worrying about something might pop up every year. – Beaumont

Participants watched the well woman exam video on the website as well, and liked it because it quickly explained what to expect when they go in for an exam. They said the visuals and the voiceover kept their attention, and they could see it being an ad on YouTube that plays before another video.



<u>PowerMeA2Z.org</u>: While women liked this site, participants found the look and feel of the *Healthy Waco Women* website more appealing to their age group. Some women said that this site seemed busier than the Waco site, and had too much text for them. Participants did like the different audience portals on the home page so users can navigate the site as either a single person, a person in a relationship, or a person with children.

I really like how it gives you options. It's Power Yourself, Power of Two. Power Your Family. You get to choose different options. – Tyler



ShowYourLoveToday.com: The reactions to this site and campaign were mixed. In many groups, participants pointed out that the site included images diverse people and information for the LGBTQ community, saying that they appreciated that the site was inclusive of many different people. They also liked that the site included an embedded Twitter feed that they could scroll through. In a couple groups, it was the favorite of the websites tested; other groups reported that they would be unlikely to revisit the site because it did not draw their attention. Some women were not sure what the purpose of

this site was, and felt that it was for people trying to get pregnant. Some participants liked the messages about health they saw on the site. For example, multiple participants liked the Well Visit 101 page because they wanted more information about to what to expect at a well woman exam. Some women noted that they liked reading the testimonials.

The logo one reminds me of a lot of logos they use for women or when you're pregnant or have a child or something. – Laredo

Participant 1: Sometimes it feels good to know you're not the only one going through something.

Participant 2: *Yeah, it's like other people made it through it so you can do the same.*-Beaumont



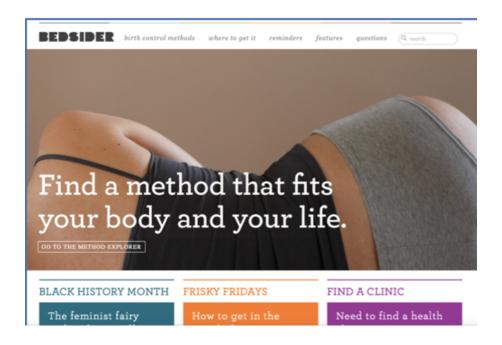
<u>Bedsider.com</u>: This site was well liked by most women in the groups. Participants said that they appreciated the large images and interesting topics organized similar to a social media newsfeed where they could scroll through various articles without having to do a lot of clicking. Several women thought the articles were funny, and liked the mix of humor with important health information. Women liked that the site seems targeted to young people like themselves. A few women thought the site was for women younger than themselves, like high schoolers.

Participant 1: "How to transform yourself into a boss bitch in only one day." (Laughter.) That's awesome.

Participant 2: I see some helpful things, too, like about the HPV vaccine because you can take it when you're older now. That's a recent development that I think most people don't know about.

Participant 3: Also the "self-care for when you feel like the whole world is ending."

-Tyler



## Conclusion

While the preconception women in these focus groups think about a variety of health concerns, STDs and STD testing were top-of-mind for these young women. Many said that mental health issues, especially depression and anxiety, are also high on their lists of concerns. Participants reported that they want self care information to help manage those mental health issues and the stress they experience around work, school, and finances.

There are clear barriers to healthcare access. When asked what may prevent them from addressing their health concerns, many women brought up not being able to afford doctor visits, because they either did not have health insurance, or their insurance did not significantly offset the cost of care. Despite this, some women in each city knew of clinics or programs through which they could access low-cost care, but said they did not feel these are well known in their communities. About half of participants had health insurance.

As a result, these young women often address their health concerns by turning to Google. Some talk to their mothers or friends about their issues, and most do not have a trusted or consistent healthcare provider they feel like they can go to with their concerns.

Overall, the only preventative care participants reported receiving is STD testing, birth control consultations, and, for some, well woman exams. Some women said they only go to the doctor if they are acutely ill or need to renew prescriptions such as birth control.

Participants had mixed experiences and knowledge about well woman exams. Some participants had had a well woman exam in the past year, while others said they had had one in the past, but not this year. When asked why they had not had a well woman exam in the past year, participants said that they do not have the money to go to the doctor, that they feel well, that they would not want to receive bad news from the doctor, and that they are scared that the exam itself is painful. There were a few women in each group who did not know what a well woman exam was at all. When asked what would make them more likely to go to their annual well woman exam, participants wanted to know how much it would cost and what exactly to expect before going.

Based on conversations in the groups, these young women were not well educated about birth control. Women in each community had questions about the mechanics and side effects of various birth control methods. A notable number of women expressed a

lack of trust in regards to their healthcare provider and birth control. Some said they believed their provider had an ulterior motive, which included making money by prescribing certain methods. Some women reported that they were not currently on birth control because of unanswered questions about how different methods will affect their bodies.

Given that they see their healthcare providers infrequently and often for brief visits, the women discussed how else they get information about staying healthy. They reported consulting with family, friends, health classes in school, and online, either through Google, YouTube, or social media platforms like Facebook. Pinterest, YouTube, and Instagram. It was clear from the responses that traditional ad campaigns that rely on network ads or radio ads will not reach this generation because they do not watch traditional cable television or standard networks or listen to traditional radio. They use social media and streaming options for entertainment.

The participants were shown various health promotion campaigns and resources. For most, the *Healthy Waco Women* Life Plan was the favorite of the three life plans tested. They liked the color palette, topics, and local resources list. They liked the accompanying website for the same reasons. When asked if they would like to receive information from these tools online, women agreed that excerpts of information such as the vitamin and birth control charts would catch their eye on social media networks like Facebook and Instagram. Some women did say that they would still like to have the paper version of the information to pick up and easily reference, and that could be a "starting place" for finding out more online. These preconception women also liked the fun, young tone and social feed-like design of Bedsider.com, and the inclusion of a Twitter feed and pictures of diverse people on Show YourLoveToday.com.

Overall, campaigns aimed at a future pregnancy did not resonate with these participants, but they were interested in getting more general and age-specific health information relevant to their current lifestyles.

# **Interconception Women**

## **Participants**

SUMA conducted five focus groups during the fall of 2018 with mothers in the interconception phase (between pregnancies). Each group included between 8 and 10 participants. The groups included Spanish speakers as well as Caucasian, Hispanic and African American women. Table 2 offers a summary of participants by location.

Table 2: Participants (N = 44)

Location	Participants
Dallas	10
San Antonio (Spanish)	8
Tyler	8
Amarillo	10
Beaumont (African American)	8

# **Lines of Inquiry**

SUMA researchers used the following lines of inquiry to capture interception women's perceptions related to health and healthcare services. The focus group guide is included in the Appendix.

- ◆ Discussion of health concerns, priorities, and behaviors after pregnancy/in the interconception period and in general
- ♦ Postpartum care and experiences
- ♦ Knowledge and behaviors around pregnancy spacing and birth control options
- Knowledge and behaviors regarding preventative care/well woman exams
- Sources for health and nutrition information, including media and social media use and habits
- ◆ Feedback on health education materials related to women's health, birth control, birth spacing, and infant care

## **Detailed Findings**

### **Health Concerns**

In an icebreaker discussion at the beginning of each focus group, the moderator spread out image cards (as described in the Methodology section). Participants each selected one image to best illustrate their largest health concern after having a baby.

While a few participants chose images showing an easy time postpartum, most chose images representing substantial struggles and difficulty or concerns about getting their body back after pregnancy. In every group, at least three participants described symptoms of postpartum anxiety and depression. Some participants described life-threatening medical experiences. Participants spoke about how these conditions were exacerbated by a lack of access to healthcare and community support.

Some common themes from the discussions included:

- ♦ High-risk conditions
- Struggles with anxiety and/or depression
- Unplanned pregnancy and birth control failure
- ♦ Lack of access to insurance or affordable healthcare
- Feeling too overwhelmed for self care
- Concerns about weight and getting their bodies back after pregnancy
- Fear of not being able to care for children

I felt depressed; I didn't come out of bed with both of them. ... I didn't want to take a bath, I didn't want to feed them. I didn't care about anything, but my husband didn't want me to ask for medical help because he knew that I was going to end up staying there for a week or three days, and he wanted me to be at home taking care of the children.

- San Antonio (wrinkled painting of woman)

My last child, I gained a lot of weight, that's one of my biggest concerns right now.

- Tyler (photo of child with greyish hood by themselves.)

When I have these twins, that's what's going to be going on in my household because I already have a nine-year-old, third-grader. ... Then, on top of that, I have the two-year-old and the one-year-old that are still in diapers. ... I'm just anxious to get back to work and get everything in order because it's hard depending on other people to put them on the bus, take them to daycare. Somebody is going to have to come cook and clean. Then he works late. I feel like everything going to be burning down." – Beaumont (picture of fire)

I think that kind of represents how I felt for my own healthcare after having children. My kids are covered, but I have no health insurance. If I even had anything womanly go wrong, I wouldn't know where to turn. I wouldn't know where to go

-- Amarillo (man in boat in the middle of the lake)

After having my baby, my major preoccupation was dying because when I had my second baby I almost died. – San Antonio (Day of the Dead skulls)

# High-Risk Conditions and Lack of Access to Care

Although these participants were not screened for high-risk conditions prior to the focus groups, discussions revealed a variety of high-risk – in many cases life-threatening -- conditions that the women had experienced.

These conditions and situations included:

- Chronic back pain as a side-effect from an epidural
- Dental infections
- Depression and anxiety
- Domestic violence
- Gestational diabetes
- Heart conditions
- ♦ NICU stays
- ♦ Ovarian cysts
- Postpartum infections
- Preeclampsia
- Severe tearing

[I'm worried about] actually being there for my kids because with my five-year-old, I had preeclampsia that was undiagnosed, and she came at 29 weeks, five days. We both nearly died. – Tyler

When I was pregnant, my baby's father was very abusive and I had to be very – I thought that I would've gone to Heaven, like he's pointing up. It was very traumatic for me because of the birth of my baby and the abusive father. – San Antonio

I had my third one natural, but all the other ones were epidural, and I can still feel it now. There's times, especially when the weather, or if I sit a certain way, or just even walking, sometimes I feel a pain where the epidural spot is, down to the side. – Amarillo

I had kind of like a traumatic [sic] during birthing my son, and I ended up tearing really, really bad. It was to the point where I needed a diaper, and it was just – I couldn't hold anything. It was horrible. – Amarillo

My heart is only functioning at 20%. Mind you, I have to go home – after I got out the hospital, go home, look at my kid's face. I don't know if I'm going to be here. – Beaumont

These conditions were very severe, and require medical follow up. However, many participants struggled to find adequate care – either because of cost, lack of insurance, lack of resources, or lack of childcare and family support. As a result of these barriers to care, participants were at risk of severe health consequences.

I got home and I had a terrible infection, that I didn't know it was an infection. ... I lasted a week like that. I couldn't get up from my bed. I had lots of fever. ... When I called my husband, I told him, "Take me to the hospital." He said, "Find somebody to take you." ... They took my baby away from me and I was hospitalized. They told me that if I had been like that one more day I would've died. – San Antonio

Not knowing where to go for those for woman needs if you don't have health insurance. Where do you – where could you go? Even urgent care, they don't do women stuff. If it's anything to do with your girl parts, they're like, "No, you need to see an OB."

- Amarillo

# **Top Health Priorities**

After discussing health concerns in the opening photo exercise, participants were asked to rank their most important health priorities. In addition to the high-risk conditions listed above, there were several common themes, including:

- ♦ Anxiety and depression
- Ability to find affordable insurance and healthcare
- ♦ Weight
- ♦ Blood pressure
- Where to go to get healthcare
- Chronic pain
- ♦ Diabetes
- Getting body back after pregnancy
- ♦ Nutrition
- Birth control and STDs
- Being taken seriously by doctors

Of these, depression and anxiety were most frequently cited as concerns, with more than half the participants in each group listing them as their most significant concerns. This was closely followed by finding healthcare that they could afford and concerns about weight gain.

I know I had postpartum depression with my first son, and it got really bad after my second son. – Amarillo

So, my thing was, am I going to be able to deal with [my anxiety and depression] without having healthcare because I didn't have insurance either? I still don't. Am I going to be isolating myself, just kind of watching the kids? That was my main thing. Am I going to be able to control my mental health, my anxiety, my depression and my kids, too? They're a year apart. – Tyler

My last child, I gained a lot of weight. That's one of my biggest concerns right now – Tyler

In the African American community, there was a substantial concern about being taken seriously by doctors.

When you're telling your doctor how you're feeling and they look at it as being regular symptoms or what you regularly go through as being pregnant, and it turned out to be something totally different. – Beaumont

I would tell my doctor because I was scared I was getting postpartum or something like that. They would just be like, "Oh, no, you're fine." I'm like, "No, I'm really sad for no reason." My baby's hungry, and I'm crying for no reason. I felt like nobody could help me through that. – Beaumont

In many groups, participants described a particular difficulty in getting treatment for anxiety and depression. In some cases, they found it difficult to convince doctors or family members that the depression and anxiety was real, or to gain attention for their care.

Postpartum. I think they only pay attention towards like the first three months after the baby is born and they forget to keep asking you towards the end because it's a lot of work with kids. – Dallas

While many participants spoke of seeking and finding treatment for anxiety and depression, others were hesitant to seek treatment. Some participants were afraid to seek help because they feared being hospitalized and losing their children. Others were concerned about the effect of psychiatric medications on their ability to care for their children, or the cost of treatment. In the African American community, participants expressed a hesitation to use pharmaceutical treatment and a frustration that their doctors were prescribing pharmaceuticals rather than connecting them with counseling services.

I always think maybe they're going to lock me up some place [if I talk to my doctor about depression], and they're not going to let me out. I think that they're going to place you some place away from your children, away from your family, and away from things that you have to do. Things that you have to do, not because you want to do them, because you have to do them. – San Antonio

I really didn't want to be on medications [for anxiety and depression] anymore because some of the medications I was on, they kind of make you sleepy. I know, with some things, with kids, you have to be very alert and all that. So, my thing was, am I going to be able to deal with this without having healthcare? Because I didn't have insurance either."

– Tyler

I think, as far as medications, with the depression and stuff, us as a black community, are scared of pills. You see so much abuse. – Beaumont

Many participants reported that barriers to care, such as a lack of insurance or because of the impact of mental health symptoms on their ability to function, caused them to delay seeking care for high-risk conditions. This delay exacerbated health conditions and also meant that a number of women did not seek or receive healthcare for new symptoms that emerged in the postpartum period and beyond either.

[My biggest concern] is lack of insurance, which with that I really just don't do anything about my own health, honestly. I don't do anything. – Amarillo

I also have cysts in my ovaries. They haven't been able to get rid of them because I need to lose weight first, and I've gained weight because of my depression. – San Antonio

## **Addressing Health Concerns**

When asked what they do about addressing their health concerns, only a very few participants spoke about seeking medical treatment, and that was usually for acute conditions like depression, preeclampsia, a heart condition, or another immediate medical problem.

*I went to the doctor. My anemia was very severe.* **– San Antonio** 

There's a place here called Family Circle of Care that does sliding scale fee. Even though my husband does make so much that we can't — makes too much so we can't get Medicaid or whatever it is, but yet, he doesn't have insurance at his job. You kind of have to go with the — I went with a sliding scale fee, where I pay \$30 to see a doctor. — Tyler

More frequently, participants spoke about trying to find other sources of support first before going to the doctor. Many times this was because they were hesitant to seek care because of cost, not knowing where to go, of the risk of getting sick from the waiting room, and of a lack of childcare.

Some participants expressed feelings of being very much on their own to when it comes to their health concerns.

You can't really talk to anybody. You could try to talk to the kid's dad. They don't understand. – Beaumont

Otherwise, women are looking at the following sources for information about their health concerns:

- ♦ Their mothers
- Other family and friends
- ♦ Google
- ♦ YouTube
- ♦ Facebook groups

I talk to my aunt. She's like my mom. She's like my best friend. - San Antonio

The women from my church, they're a good resource. - Tyler

I was going to say Google or other mom groups on Facebook, to maybe talk to other people that might be experiencing some of the same things I am. – Amarillo

The power of Facebook as a source of information about health concerns and support is significant. Virtually every participant was a member of a moms' group on Facebook, and several were also members of health-related groups. They stated that they go there for information, assistance, and emotional support. These participants often turned to Facebook groups before seeking other medical assistance in hopes of finding either alternatives to provider visits or affordable sources of care.

I know, as far as me, with twins, they have a bunch of twin groups, black moms, moms of twins, people with whatever I got going on. You're actually talking to people.

#### - Beaumont

It gives you the confidence that maybe since she got something taken care of, maybe there is hope that I can. – Amarillo

That's actually how I got into more therapy because at first I said no, I didn't want to. It was hard. I just stayed to myself and then I would go into the group and comment things. Somebody put it on, "No, you need to talk to somebody. That is not healthy." – Dallas

## **Barriers to Care**

The cost of healthcare, lack of health insurance, and lack of affordable care created very real barriers for many of the mothers in these groups.

Participants mentioned the following barriers:

- ♦ Lack of health insurance
- Cost of healthcare
- ♦ Not knowing where to go to get care
- Difficulty navigating the maze of referrals particularly without health insurance
- Doctors not taking them seriously
- ♦ Lack of family support
- ♦ Having multiple high-risk conditions
- Fear of not being able to take care of children
- ◆ Lack of childcare options
- Reluctance to use pharmaceutical support for depression
- ♦ Poor education about birth control

I think it's very difficult for a mom to look for help when you have your children by the hand all the time. It's very difficult to go to the doctor because you have to be taking care of your children. I think that's why we don't look for help because just making it over there, then waiting for two hours. – San Antonio

I looked for help elsewhere because I didn't have insurance so I couldn't look for help there or at the doctor's office or places like that. I couldn't look in places like that because I had to pay cash. – San Antonio

# Postpartum Care and Experiences

All but one of the participants went to at least one postpartum visit. Many indicated that they might have wanted additional follow-up care but were prevented because Medicaid only provides maternal coverage for 60 days after giving birth. After that, they may not have had the resources to continue receiving care.

*That's the only [visit] that Medicaid pays for. -* San Antonio

While some participants had longstanding relationships with their doctors and described in-depth conversations with them, others expressed opinions that they were not well-taken care of in postpartum visits and did not feel like they were heard.

We talked about different styles or educating contraceptive and whether they're going to be effective or not. ... When I go in I kind of run the show because my doctor is like family to me. – Dallas

They covered everything, besides the fact that they didn't really answer to my questions about being depressed, but other than that, I guess they told me what they were supposed to tell me. – Beaumont

You're not just a dollar amount. You're an actual person with feelings.—Tyler

Participants mentioned the following topics being discussed in the postpartum visits:

- ♦ Birth control methods
- Postpartum depression
- ♦ Follow-up on wound care
- ♦ Breastfeeding
- Follow-up on high-risk conditions

Conversations about birth control were the primary topic reported in postpartum visits. Participants said their doctors offered tubal ligations ("tubes tied"), IUD's, pills, injections, and implantable options. While a few participants stated that their doctors worked with them to explain the various options, many participants expressed feelings that the providers were pushing birth control too quickly and forcefully.

My doctor was insistent that I should have the injections or the implants or anything else. – San Antonio

I feel like they need to ask you if you would like birth control, not automatically assume that because you've had a kid you want birth control right away. – Amarillo

# Breastfeeding

During the postpartum visits, many participants reported that their doctors also asked about breastfeeding, but the mothers stated that the conversations centered more on the benefits of breastfeeding or on checking the baby's health and weight rather than on discussing the mechanics and difficulties involved with breastfeeding.

They just asked if you still were, but only because they're going to try to give you medicine, and if you're breastfeeding they can't give you that medicine. – Tyler

My doctor asked if I was [breastfeeding], and how it was going, and how long I planned to do it. I told her I planned to do it as long as I could. Thankfully, the baby was breastfeeding a while, but it's hard and exhausting. She asked if I wanted to supplement with the formula. – Dallas

Participants stated they were getting most of their breastfeeding information at the hospital, and identified community sources like WIC, La Leche League, and friends/family as sources for getting more breastfeeding help.

I went to WIC, I heard it there. How to hold a baby and how to help her latch on.

- San Antonio

## Safe Sleep

When asked about safe sleep methods and messages, participants were aware that having babies sleep on their backs, away from pillows and loose blankets, and not in their parents' beds would reduce the risk of Sudden Infant Death Syndrome (SIDS). Very few – if any – participants had been told that breastfeeding reduces the risk of SIDS too.

Participants identified multiple sources for getting these messages including:

- Advertising campaigns
- ♦ Doctors
- Mom groups
- Hospitals
- ♦ WIC

The little baby, when it's sleeping in the crib – that commercial – it's like, "Don't sleep with blankets, no stuffed animals," but you'll get it at the hospital all the time.

- Beaumont

In the hospital. When I gave birth and stuff and they brought him to me. They pretty much tell you don't sleep with him in the bed. – Amarillo

Most participants followed these recommendations. However, those that didn't cited the challenges of exhaustion and financial circumstances as barriers to following the safe sleep recommendations.

I was homeless at the time, when I had him. We were sleeping on somebody's living room, four other people in the living room. There really wasn't much space for the playpen or the crib. – Tyler

I couldn't get out of bed. She had to stay with me because I couldn't lift her up out of the little bassinet or crib or whatever. — Tyler

I heard you're not supposed to let the baby sleep in the bed, but when it's 3 in the morning and I'm tired, you're going to sleep in the bed with me. – Dallas

## **Pregnancy Spacing Knowledge and Behaviors**

To gauge reactions and knowledge about family planning and pregnancy spacing, participants were asked about the messages they got from their doctors, and their opinions on why the Centers for Disease Control and Prevention (CDC) would recommend an 18 to 24 month waiting period before trying to conceive again.

A few participants had taken time to discuss family planning with their partners, and had made a joint decision about when to have their babies.

Most participants had not planned out the timing of their pregnancies. Many were unexpected pregnancies, often the result of problems with birth control. These included having a bad reaction to the Depo-Provera shot, failed birth control pills, having an implant fall apart and have to be surgically removed, or simply not using birth control at all.

That's how mine was. Except my second child I was on birth control when I got pregnant with her. She was not a mistake, but I didn't expect for it to happen. – Amarillo

I didn't decide. I was having a problem with a device, I had it removed, and a month later I was pregnant. – San Antonio

It was failed birth control. – Dallas

God decided for me. - Tyler

It was apparent that many participants lacked education on efficacy and likelihood of side effects of their various birth control options. This left many unsure of what safe options may be available to them, leading to unexpected pregnancies.

I haven't gotten back on [birth control] because you just hear many bad things about what it does to people. The arm implant gets stuck in you. The IUD can break. You just

can't take this shot out. You going to have to let that run its course. I don't know what is safe. I don't want to have any more kids. – Beaumont

Participants' responses indicated that many doctors are recommending birth control options – to the point of appearing pushy. However, responses also indicated that it is difficult for doctors to offer comprehensive birth control education during a single postpartum visit, and not all doctors are able to cover the full range of details during prenatal care visits or well woman exams either.

I don't know why they don't teach you that if you take an antibiotic while you're taking those pills that they cancel each other out. Nobody ever told me that. – Dallas

Mine was just – he had a lot of patients. Basically, you were a one-second thing. He was a great doctor for me when I was pregnant, did a great delivery, but you don't get to talk about anything you really need to. I didn't really get any help with anything. – Tyler

Some participants attempted to get permanent birth control through tubal ligation, but faced religious and administrative barriers.

I gave birth at Mother Frances, and they won't tie your tubes there because it's a Catholic hospital. – Tyler

I was going to get my tubes tied and everything, but I didn't realize you had to sign the papers within 30 days of something, and I didn't. My doctor didn't push that on me. He knew that that's what I wanted. When it came time to do the C-section, he was like, "You didn't sign the papers. You can't get your tubes tied." – Tyler

None of these participants had heard the CDC pregnancy spacing recommendation of waiting 18 to 24 months before getting pregnant. Most had been told merely to wait 6 weeks after birth to let their bodies heal before beginning sexual relations. When told the CDC recommendations, participants guessed that they were to let your body recover from the trauma of childbearing and childbirth. Others felt it might be good because of child development.

It takes that long for your body to completely heal, but I've never heard that from a doctor. - Dallas

Body needs a year to heal itself. When you have kids back to back to back, you can't fully recover. That's your mind. That's your insides. That's everything. – Beaumont

A lot of people go through postpartum depression and then you need time to give that baby that certain type of love to help them grow first before you bring another one into the picture. -- Dallas

However, some respondents were not receptive to doctors' suggestions or public health recommendations that they wait longer to have children. They viewed it as a judgement on their decision about when to get pregnant and how to plan their families.

I don't think that way because it's not really their choice. We could get pregnant tomorrow, if we want. – Beaumont

## **Power Your Family Pamphlet**

Participants were shown a pamphlet designed to help women and families make educated decisions about birth spacing. More information can be found in the Materials Descriptions section.

Participants responded very favorably to this resource. They liked the photos, the colors, and the layout of the brochure. Many appreciated the tone, and talked



about the questions about the stability of the relationship with a spouse, finances, or how a new baby would affect their existing child(ren).

I liked that it was talking – it says, "Power me," like as the mom versus, like a lot of the focus is always on the baby. How is the baby doing, and then there's always that at the end of the session, "How are you?" – Dallas

I like where it talks about are you in a healthy relationship, because when I got pregnant with my second I was not, so I was just miserable. That was something that I was glad that they included in it. – Dallas

I like what it says here, "Is your body ready? Are you exhausted?" That is true. It's very exhausting to have two children. – San Antonio

I guess it kind of gives you another look at it, to look at am I financially stable? Do I have a job, to take care of this other kid, healthcare for this other kid? – Amarillo

Many women stated that having access to this information before their pregnancies might have changed their minds about pregnancy spacing.

I wish I would've had this after my son because I know all this now. I know when my daughter, my body was starting to tear itself down when I got pregnant with her. Now I know I wasn't in a healthy relationship. Now I know if it was best for my son or not, but after my son I really wish I would've had something like this. -- Amarillo

My main takeaway is something like this would've been helpful for me. I thought that I was ready again, but now having stopped nursing my last baby – I spent the last six years constantly pregnant or breastfeeding and never had any time to get my body back. ... I was looking more of a family aspect of it, like we want our kids close in age. I was a little bit older when I had them, but seeing the science behind it might've maybe changed my mind. -- Dallas

### Well Woman Exams

Participants were asked questions about the frequency that they sought preventative care and well woman exams, why they might or might not be seeking regular care, and what they thought should be included in a well woman exam.

When asked what came to mind about these exams, participants identified many common topics and procedures:

- ♦ Pelvic exam
- ♦ Pap smear
- Mammogram/breast exam
- ♦ STD's
- Discussing and obtaining birth control
- ♦ Blood work
- ♦ Urine sample

Many participants reported that they do seek well woman care from their OB/GYN (obstetrician/gynecologist) office, a women's clinic, a family care physician, or a general practitioner. Most participants did get their well woman exams once per year. They stated that they seek the exams in order to obtain birth control. Others go because their doctor's office reminds them or just because they are following their doctor's recommendation.

I've definitely not had a well woman exam since my children, but pre-children it was always for birth control. You had to have your Pap smear to get your birth control.

- Amarillo

Honestly, yeah, if I don't go then they won't renew the prescriptions or anything like that, so that makes me motivated to go every year. – Dallas

When asked about the barriers to getting an exam, participants listed:

- ♦ Lack of insurance
- Not knowing where to go
- ♦ Embarrassment
- Fear of finding something wrong
- Discomfort

If there's not a clinic there that helps with it. In my hometown they have a clinic there that you can go right down and everything is free. When I moved to Amarillo I was kind of like, "I need birth control. Where do I go? I have no insurance. There's no place here like that." I was lost. I didn't know what to do. – Amarillo

I don't have the insurance to pay for both of these because it's \$300-something for the well woman. So, I just kind of say, "They'd find something, if they thought something was wrong." I guess I just kind of think that way. – Tyler

#### PowerMeA2Z Website

The responses to this website were very favorable. (More information about it available in the Materials Description section.) When asked who they thought the website was designed for, participants correctly identified that it was for women and possibly families. They thought that the content was interesting and presented in a way that was very engaging and accessible. They particularly liked the vitamin quiz and the way questions were posed to bring a reader further into the site.

I think it's great because it also has questions for you, you yourself, where it says, "Are you taking care of yourself?" There's several questions there where they tell you what are the different birth control methods, are you eating the right foods, are vaccinations only for the children? There's some interesting questions in here that you ask yourself, and it helps you to look further for information. – San Antonio



I noticed it has links for how often do I have the blues, what can I do to control stress, how much is too much alcohol. That seems like it's kind of informative, to give you tips for the postpartum depression, am I having these kind of signs. – Amarillo

They also felt the tone of the site encouraged them to engage and get more detailed information.

I don't feel any judgment from it. I feel like it's kind of for any woman. You can kind of pick and choose what you wanted to use from it. I don't feel like it's pushing you one way or another; I feel like it's just out there for information. You can choose any of them, so whatever fits you at that time. – Amarillo

They stated that they would be likely to use a website like this that provided links and resources for women in Texas,

Texas needs one. - Beaumont.

# Interconception Health Knowledge and Behaviors

In order to gauge knowledge and behavior around interconception health, participants were first asked questions about where they would go for information on health and fitness more generally. They were also shown various educational materials related to women's health, infant health, and parenting, and asked about their media consumption habits.

When asked where they go to get information about their diet, fitness, and wellness, participants did not mention their healthcare providers. Only one participant in Dallas mentioned going to their doctor or a nutritionist for help.

Instead, the mothers in the focus groups mentioned the following sources of information:

- ♦ Friends/family
- Facebook groups (moms or fitness-related groups)
- ♦ Google
- ◆ Programs (e.g., Weight Watchers)
- ◆ Fitness apps (e.g., MyFitnessPal)

Everything that I have learned about how to take care of myself better has been in Facebook groups. – San Antonio

I have apps on my phone. There's all kinds of apps for women's health, staying healthy, what exercises you should do. -- Amarillo

Many participants expressed skepticism about marketing materials from diet companies in particular and prefer to get information from real people who have had success.

For me, it's not advertising. It's people with the results. - Tyler

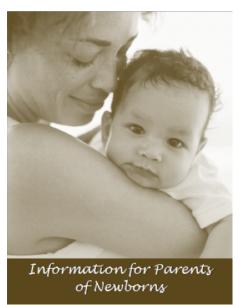
I get into groups and I start reading publications. Then I start finding out if the product works or doesn't work, the product that they're talking about. – San Antonio

#### **Texas DSHS Information for Parents of Newborns**

At first glance, the participants liked the information included in this booklet. They described it as comprehensive and full of information that they would need in the early days of caring for a child.

It gives you information from everything, from the time that the baby's born until you can get him out of the hospital, even the car seat, vaccinations, too. – San Antonio

It's informative. It's got about shots, it's got, as far as early childhood intervention, the programs that they have for that. It's got a lot of information. – Amarillo



Although participants were interested in the specific content in this pamphlet, they did not find its presentation engaging. They stated that they were unlikely to read it in its current layout because the text was too dense. They wanted more pictures and colors, and they wanted to be able to find the information that they needed easily when they needed it. They suggested that it should be redesigned in a way that had more broken out sections, more bullets, and a better table of contents.

If it were me, I would make it smaller and thicker, and with more color and more pictures because to open this up and see all like this long sheet of words I'm not going to read it.

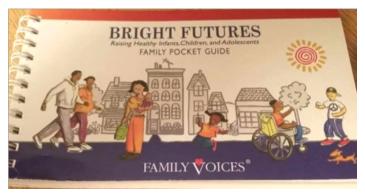
- Dallas

I was thinking maybe if some of these topics covered were even put on the front of it. That way you know kind of what you're picking up, what you're getting into. – Amarillo

### **Bright Futures Pocket Guide**

Participants were then presented with two alternate layout options for content. They liked the smaller, more durable and more colorful *Bright Futures Pocket Guide*, especially the:

- Colors
- Photos
- Tabs to organize information
- Smaller amounts of information on each page
- Durable pages so that it would survive diaper bag use



This is more like my level because it's easier to read, it's not as intimidating because there's smaller sections of words, and then it's easy to navigate on the side to infancy, toddler, or early childhood. -- Dallas

The color-coded tabs for information, that would be very helpful. -- Tyler

#### **Loving Support Keychain**

The second format option was a keychain. Many participants responded well to this layout because they liked being able to clip it to their diaper bags and use their phones to look up the information on the go. Some had received a similar keychain from WIC and had used it frequently.

Everybody, nowadays, have a cell phone or a tablet. Everybody has keys or a backpack they're going to hook this on. Trust me, that's going to be much more — somebody is going to be like, "Wait, I can look this up for this right here." -- Beaumont

When asked to choose between the *Bright Futures* booklet or the keychain style, participants were split. Some preferred the keychain, because they use their phones so much to look up information and liked how portable It was. Others stated that they didn't want to rely on their phones when they were on the go or while breastfeeding or caring for their baby. When asked to vote, most voted that they wanted both approaches to offering the information.



I'm a reader at home, but on the go, like I say, I might just have my phone with me.

- Beaumont

# Birth Control After Baby Booklet

There was an immediate positive response to this booklet. In each group, participants visibly paused to review and engage with the resource.

*I really like this book.* – Beaumont

I like, overall, how it was displayed and organized. It's very visually appealing. - Tyler

I like the "how much does it cost" page. That's cool." - Tyler

I liked that it was kind of more durable than just paper, and the colors. What caught my attention, really, was the happy smiles right from the beginning. That was nice.

-- Amarillo

Many of the mothers said that they wished they had had this resource, because it laid out the positives and negatives of their birth control options in a way that made them feel like they could make an informed decision.

Yeah, they don't tell you the negative side effects because the thing is, we've probably all been on birth control at some point, and obviously, we got off of it, or we might've got pregnant while using it. – Beaumont

Yeah. I like the chart at the very last page. It's just really easy to read, just to compare contraceptives. It's just so easy. -- Dallas

Participants liked the fact that it didn't just talk about birth control, but offered a more holistic approach to postpartum health. Participants specifically liked that it touched on mental health resources, vitamins, and that it had suggestions and space where women could write notes and plan out how to talk with their doctors about postpartum issues.

The postpartum appointments, like what questions you should ask your doctor. There's a lot of women that go, and they're just quiet, waiting to see what the doctor's going to say, but they don't really ask any questions. Basically, they just go based on whatever the doctor's saying. If the doctor says, "Does it hurt here?" They just say yes or no. They don't ask questions. – San Antonio

I really like the vitamin part, where it tells you what vitamins, what they help with, where you can get them from, because every time I take a vitamin, I'm all, "What does this do?" I think, if I had a chart like this, and you can study it. – Beaumont

Participants also commented that they liked how this resource included information for men too, because it empowered both women and men to make birth control decisions.

I learned something new about – because I would like my husband to have a vasectomy so that I don't have to suffer the consequences of birth control pills or birth control devices for women. That's an interesting section for me because it is reversible. – San Antonio

Overall, participants stated that, if their doctor gave them this pamphlet, they were likely to read it. Some even asked if they could take a copy home with them to give to a pregnant relative.

# baby gooroo Charm Bracelet



In Tyler, this postpartum charm bracelet was tested as a possible intervention to incentivize and motivate mothers to engage in specific health behaviors/activities. For example, women could earn a charm each for attending a doctor's visit, nutrition class, and a parenting class. More information on the bracelet is available in the Materials Descriptions section.

Most participants liked this item and stated that they would find this kind of bracelet motivating. However, participants said that, if the classes were not well done, or particularly informative, the bracelet would not be

enough to inspire them to attend.

I think it'd be neat for a period of time, but overall, I don't know, for sure, that that, itself, would motivate me. The going and having maybe a successful group session or actual class, that would probably motivate me more than the charm itself. – Tyler

#### Media and Social Media Use

Participants were next asked about their social and traditional media usage, including internet, television, and broadcast media.

Responses indicate that social media is a large part of these women's lives. They turn to it for connection, support, childcare information, guidance on healthcare access, health and fitness advice, and general life research.

The most common platforms (from most to least used) are:

- Facebook (particularly groups)
- Instagram
- Snapchat (for keeping in touch with family)
- Twitter

Facebook is the predominant platform amongst this group for finding connection and information. Through 10 hours of focus group transcripts, it was mentioned 99 times. Nearly every participant was part of a moms' group on Facebook – whether they post or not – and they often look to it to find information. Here are some of the reasons that participants turned to Facebook:

- Connect with other mothers
- Find weekend events
- Get health and fitness tips
- Work
- Connect with family
- Makeup tips
- Personal care

As mentioned in the section on health concerns, many participants turn to Facebook groups before a medical professional.

[I use Facebook for] everything ... To connect with family. There's a marketplace on there.

There's a bunch of different groups for mothers, for all kinds of stuff. Pretty much everything. –

Amarillo

While some participants mentioned getting fitness tips on Instagram, it was mentioned less as an information source than Facebook. Participants' descriptions of their Snapchat use was more personal.

I like Snapchat, but more of a personal thing. - Beaumont

Not health-related, but I have gotten stuff on Instagram. It's like easy picks or something like that. It's about getting a shoe subscription for kids and then you can return the shoes.
-- Dallas

When asked about other media use, it was very clear that these participants rarely watch cable or broadcast television; they may listen to radio while they are in the car.

I pay for cable, but really, the TV that I watch I don't need cable for. - San Antonio
I listen to the radio when I'm going back and forth to work in my car. - Dallas
If I do znatch TV zna'll znatch for the chorn and the minute the commercial commercial commercial.

If I do watch TV, we'll watch for the show and the minute the commercial comes on everybody is whipping out their phones and looking at Facebook again. – Amarillo

Instead, participants reported using online platforms to stream media. For video, they turn to:

- ♦ YouTube
- Netflix
- ♦ Hulu
- ♦ Amazon

While many have Netflix, which does not have advertisements, some watch Hulu and YouTube, which do have advertisements. Participants reported that they don't typically pay for the premium versions of Hulu or YouTube that allow them to skip ads.

I do watch some [ads], but like Hulu. There's commercials on Hulu, and you can't skip them unless you have another and that's where I watch commercials. – San Antonio

For music, many participants reported that they listen to streaming services, such as:

- ♦ Pandora
- ♦ Spotify
- ♦ Apple Music
- ♦ iHeartRadio
- ♦ SoundCloud

Of these, Pandora was slightly more popular than Spotify; these two were more commonly cited by participants overall than the others. For the most part, participants were using the free versions of Pandora and Spotify that include commercials with no option to skip. They stated that sometimes they ignore the commercials, but they do pay attention to ones that are "catchy."

Some ads you pay no attention to, and others have this catchy little jingle that you find yourself singing the rest of the day. – Dallas

When asked about radio ads that had caught their attention, participants cited an ad that encouraged getting an HPV vaccination, and a Subway Restaurants ad.

Focus group moderators asked participants where else they would see – or would like to see – resources and educational information. They recommended advertising on Facebook, Google, or placing marketing materials in stores where they purchase things for their children, like Carters or Walmart. They also suggested working with insurance companies to send items directly to the home. The mothers stated that they would be likely to click on an engaging online ad that would offer them the kinds of information that they talked about in the focus group.

[Put ads] where you shop for your kids. Offer support and help coupons. - Beaumont

If – say, I was to get pregnant again and I got a new healthcare provider. The insurance company sends you packets when your insurance changes. I feel like, if they would include those, I would read them. – Tyler

If they had something [on a Facebook ad] that was really a question that I had, like how to get your child to do this, or something that I was already thinking, then I would click on it because they're going to answer my question. – Dallas

### **Participant Takeaways**

At the end of each focus group, participants were asked what they thought were the most interesting or important things they had learned. The main responses included:

- Birth control pamphlet
- Birth spacing pamphlet
- ♦ The need for vitamins and folic acid
- Varying experiences with doctors
- ♦ Resources to help with depression
- Learning that they were not alone in their feelings and struggles

Overall, participants valued the opportunity to be among other mothers of young children to be able to get together to talk about the issues that they face. Participants gave responses that indicated just talking about their issues was a valuable form of mental health support in itself.

I found out that a lot of – it's really common to go through all that stuff that we're going through. I haven't really had a bunch of moms to hang with or sit down and talk to, relate to. Now I don't feel so crazy and out of place. – Beaumont

This focus group has made me feel a little better about some of the stuff that I feel about this baby and with the baby. – Dallas

#### Conclusion

The mothers in these focus groups reliably accesses well woman preventative care, but had faced a number of very intense medical circumstances and high-risk conditions surrounding their pregnancies. Postpartum depression and anxiety were especially prominent, yet resources for help are lacking.

Despite the knowledge that they need to follow up on health conditions and issues with continued care, access to resources is difficult. A lack of insurance or high costs can make it difficult to afford medical care, and access to more affordable options can be extremely limited. Many only go to a medical professional in emergency situations. Instead, they turn to friends, family, and online resources such as Facebook for information first.

Even for those with healthcare coverage, the challenge of taking care of multiple children and/or the inability to miss work is overwhelming. So many of the mothers are too overwhelmed for self care activities.

On top of this, a lack of education about birth spacing and birth control, combined with a lack of access to reliable birth control methods, is creating unplanned, closely spaced pregnancies.

These women welcome up-to-date and accurate information about health and wellness if it is delivered in an engaging and empathetic way. They are open to attractive, straightforward pamphlets, social media outreach, and educational websites that are designed with their realities and needs in mind.

# Women with High-Risk Pregnancies

#### **Participants**

SUMA conducted five focus groups during the fall of 2018 with women who had experienced a health challenge during their most recent pregnancies for pregnancies within the past two years. For some, this had been their first pregnancy, but the majority of participants already had other children. Table 3 offers a summary of the participants.

Table 3: Participants (N = 34)

Location	Participants
Dallas	10
San Antonio (Spanish)	4
Tyler	8
Laredo	4
Beaumont (African American)	8

# **Lines of Inquiry**

The guide for the high-risk pregnancy focus groups is included in the Appendix. The lines of inquiry included:

- Current health concerns, priorities, and behaviors
- Discussion of participants' high-risk pregnancy and postpartum conditions and experiences
- Experiences with and access to prenatal care, especially with regard to health conditions
- Hospital experiences during birth
- Discussion of the postpartum period including, healthcare, access to care, experiences with care, and general experiences/support (e.g. healing and recovery, infant care, and postpartum depression)
- Perceptions of the quality and utility of the healthcare and health education resources received
- Knowledge, perceptions, and behaviors around pregnancy spacing and birth control/family planning

- Sources of health information/education and habits around seeking health information – including from family and friends as well as print resources and media/social media channels
- A review of sample resource materials in varied formats

### **Detailed Findings**

# **Pregnancy Attitudes and Perceptions**

As discussed in the Methodology section, participants selected photo cards to represent their feelings about their most recent pregnancies. In explaining their choices, the majority of women expressed feelings of stress, isolation, anxiety, and uncertainty, while just a few shared that they felt calm, happy, or beautiful during the pregnancy.

The photo I picked is a little girl walking along the train tracks with a suitcase. ...I had a lot of anxiety when I was pregnant with my youngest child, and I chose this photo because she is alone walking by herself, but the destination really isn't clear where she's going, as well as she's on train tracks, so it could be dangerous. – Beaumont

Skull and bones. ....I just felt like I was dead. I didn't have any energy. - Dallas

It's pretty much just jumping off a cliff. - Dallas

I chose this broke down, raggedy looking shack in the middle of the lake. I was suffering

with hyperemesis – extreme nausea – and it had me hospitalized probably about a good ten times. If it wasn't that, it was the pseudo-tumors things. - Dallas

I chose the hurricane. I chose it because I think it's very chaotic. It's very hard. It's traumatizing. – Laredo

[This Day of the Dead scene] represents I felt a little bit depressed because my



father had just died. I didn't really enjoy my pregnancy like I thought I would. My oldest was nine years old, so it took me a long time to get pregnant again. I really didn't enjoy it. I wanted it so much and so much, but I was depressed and sad with diabetes and high blood pressure." – San Antonio



Like a rosary and some saints and crosses. The reason I chose this is because ...I never thought that I would have as many complications in my pregnancy. I was always bleeding. I was bedridden. I couldn't get up. They placed me on bed rest for a long time. I had a doctor, a pregnancy specialist, because I almost lost my daughter. So, I prayed a lot. - San Antonio

#### **Health Conditions**

When asked about their top of mind health concerns and the conditions they faced during their most recent pregnancies, participants listed the following:

- Advanced maternal age
- Anemia
- Anxiety and stress
- Breech position
- Chronic pain exacerbated by pregnancy
- Premature delivery/baby in NICU
- Emergency dental care
- Endometriosis
- Fibroids
- Gestational diabetes
- Hair loss
- Headaches and fatigue
- Hemorrhaging
- Hemorrhoids
- High blood pressure
- Infections (vaginal, urinary, kidney)

- Leg pain and numbness
- Lower ligament pain
- Mastitis
- Other complications with uterus and placenta
- Other mental health issues (e.g., eating disorder)
- Painful scar tissue
- Placenta previa
- Polycystic ovarian syndrome
- Postpartum depression
- Preeclampsia
- Rh sensitization
- Severe/extended nausea
- Stroke
- Thyroid condition
- Vision change
- Weight gain
- Wound care issues/infections

The most common conditions that women discussed were postpartum depression, high blood pressure, and gestational diabetes. Conditions such as anemia, placenta previa, preeclampsia, and weight gain/challenges were discussed by women in every group as well. A number of women had experienced more than one condition or concern simultaneously. Some of the conditions above were experienced more rarely, some by only one or two participants (e.g., eating disorder, wound care issues).

I suffered with a lot of depression and hypertension and preeclampsia. I want to say around 28 weeks I went into labor while I was at work. ... For about three or four days, they had to put me upside down in an obtuse kind of angle, so my cervix can close, so I wouldn't have her, and [it was] just a lot of stress. – Tyler

Sometimes it's something that you feel but you don't want to talk to your doctor or somebody else about it because you feel like you're going to be judged. "Why are you feeling that way? You just had a baby. ...You should be feeling good," but you don't. You feel badly. – San Antonio

The hemorrhaging was so scary because I had to call an ambulance. I had to go back to the hospital. My baby was only ten days old. I had to leave her behind. I lost a lot of blood. I was cold. They had to keep on piling blankets on top of me. It's just a scary experience. - Tyler

A number of the participants had had similar risks and complications, including miscarriages, during prior pregnancies as well. However, for just as many, the complications with their most recent pregnancy or birth came as a surprise; they may have had healthy pregnancies in the past or this was their first pregnancy.

Non-health challenges compounded the stress for a few participants. These included losing health insurance or insurance limitations, domestic violence/abuse, and financial issues, all of which interfered with prenatal care.

When asked who they talked to about their health conditions, symptoms, and concerns, most participants did report that they talked to their healthcare providers – usually OB/GYNs or sometimes specialists. However, several waited to reach out to their providers and chose to seek advice and support from family members and friends first, especially their mothers, those around them who were also healthcare providers (e.g., an aunt who is a nurse), and those who had other children. Women sometimes reported talking to their partners as well, but some waited to do this or did not have a reliable partner in the picture. Hesitation to reach out to providers was especially true for those who experienced depression symptoms.

I had questions, the person I would ask, they were either my mom or my friend that had the experience of having the babies. – Laredo

I talked to my mom and my best friend [about my depression symptoms]. When I told my mom, my older sister got involved. She would tell me not to be embarrassed or ashamed. I wasn't the only one that felt that way after having a baby and that I shouldn't feel insecure, because I did for a very long time. ... After that is when they went with me to go see our doctor that we've known for a very long time. He's the one that suggested treatment and medication to try to help me. – San Antonio

#### **Prenatal Care**

Nearly all of the participants received prenatal care, though its duration, frequency, and reported quality varied widely. Given their special health conditions, healthcare was especially important and impactful for this group as many were interacting with one or more providers frequently, even daily or weekly at times.

Women in the focus groups reported that they went to their healthcare providers for the first prenatal visit anywhere from a few weeks to a few months into their pregnancies. None talked about seeing providers as part of planning to conceive. Several went during their first trimesters, some went during their second trimesters, and a few went very late or not at all. These visits most typically took place at an OB/GYN office or clinic and in some cases with a primary care provider. In a few cases, participants needed emergency room care very early on in their pregnancies as well.

[I went to a healthcare provider] when I found out that I was pregnant, I started bleeding also and I went to the hospital. They said, "You're going to lose this baby. You have placenta previa." Right away I started with a specialist. – San Antonio

I went to the same doctor that I went to previously. So, they had already knew [sic] about my high-risk pregnancy with my last. Their main concern with me was mostly having another C-section so soon because my kids are only 15 months apart. There were definitely concerns about me having another C-section so soon and my risk, like high blood pressure and preeclampsia, popping up again. - Tyler

With my second pregnancy, I went late – 20 weeks. I found out when I was four weeks, but I don't know. I just didn't feel like going to the doctor. - Tyler

A number of women reported that they were comfortable talking openly with their provider(s) about their questions and concerns; however, just as many participants were not as comfortable. In most cases, women's comfort levels were directly related to

the rapport or history they had with their providers as well as the provider's style and approach or perceived caseload.

The doctor I have don't want to listen. He's always in a hurry. He's got to go. It's like you just got to deal with yourself. – Beaumont

*I think that the amount of patients that my doctor had just interfered with everything.*- Dallas

My doctor, she really listened. ...It's my body. If I feel something was wrong, to be able to discuss that with her. I had morning sickness throughout all my pregnancies. She was able to really work with me on finding a solution, not just throwing me on this medicine or this medicine and kind of hoping for an outcome. She really listened to how I was feeling and how it affected me. – Beaumont

I know he cares, but they have too many patients to have to take care. - Tyler

Participants wanted the following from their healthcare providers in order to feel as if they were receiving adequate support and quality care:

- ♦ Eye contact
- Time (not feeling rushed), including time for questions
- Someone who is sincere, cares, and takes their concerns seriously
- ♦ Someone who values their agency
- ♦ Offers specific and ongoing guidance

# **Support for Health Conditions**

All of the women in the focus groups received some sort of information and support for their specific health condition(s). However, there was wide variation in this, often depending on their specific condition, its severity, and the rapport they had with healthcare provider(s). Most commonly, women reported that they received specific guidance once they were diagnosed with a specific condition (e.g., placenta previa, gestational diabetes, high blood pressure, breech baby). A number of women received ongoing monitoring for their conditions, which may have included urine or blood labs. Some participants received referrals to specialists for additional care; this included maternal-fetal medicine specialists and mental health providers most often.

However, several women described a lack of quality care and support, including feeling as if they were not heard or understood by their healthcare providers, or that they did not receive adequate information about their risks and conditions – or had to demand answers and time.

When I would have anxiety attacks my blood pressure would shoot through the roof. I run naturally low. ...I actually passed out in the shower once. When I explained all of that to [my doctor], she was like, "I can send you for a psych consult." I was like, "Hmm, okay. I think she just thinks I'm crazy. She's trying to brush me off." I didn't feel like she really addressed it. She never even set up the consult. – Beaumont

When I asked questions, they couldn't really even explain [my condition] to me. - Tyler

I always come prepared. If I have stuff on my mind during the week, I write it down. If they don't want to make time, I'm going to ask questions so that you're going to make the time. It's my health. – Beaumont

Some women didn't feel comfortable enough with providers to disclose the extent of their symptoms/condition because they were private, fearful, or had a "stay strong" mentality. A few Hispanic and African American women in the groups mentioned that it was culturally taboo to "whine" or "complain" and the norm was just to try to be strong and rely on yourself (especially concerning mental health symptoms).

I had a [car] wreck last year, so I already had health concerns with my hip and my back and so I didn't disclose that information because I wanted to work my whole pregnancy, pretty much. I never told my doctor any of that. I was like, hopefully I don't get to the point where I have to say something and they put me on bed rest. – Dallas

I was too embarrassed to call, because I had postpartum [depression]. I had it bad with my second child. I didn't know what it was, but I knew I did not want to touch her. I did not want to be left with her. –Beaumont

Participant 1: For me, it's like everybody's pregnancy is different. No one person's pregnancy is alike, so in my family I may have said, "This is hurting," or "This is going on." [And they said,] "Oh, I didn't experience that." "That didn't happen to me." I'm like, "Just because it didn't happen to you, doesn't mean it's not happening to me." Just like in the Hispanic culture, an African American's like, "You've got to be strong, too." If you complain too much...

Participant 2: You're considered a whiner. No one wants to hear that. "Oh, here she comes. She's the whiner. Always complaining about something."

- Dallas



While many women did understand their condition(s) as a result of conversations with and resources from healthcare provider as well as personal (often internet) research, not all did. Some received conflicting instructions or mixed messages from the different doctors and providers they were working with (e.g., about taking certain medications) or not enough information overall.

They could've still given me some more tips or just more tailored to me instead of general information. - Dallas

I didn't know what I wanted to ask. - Dallas

My OB gave me, actually, a lot of information. He talked to me about the whooping cough vaccine and the flu vaccine and then the prenatals, which is the folic acid, the vitamin C, vitamin D. He just bombarded me with all this information. I was like, "Wait a minute." I was only taking one medication. Now I have to take three. – Laredo

### Classes, Resources, and Birth Preparations

Nearly all of the participants received resources of some kind during their pregnancies to help them better understand their conditions, risks, or to plan for the birth or afterwards. While several women mentioned a folder or packet or "big bag" of general pregnancy, birth, and baby information, there did not appear to be consistency in what resources women received and when. A number of women did report getting specific handouts after they were diagnosed with a certain condition to help them understand it, reverse it, or manage symptoms. Many women felt that their providers placed an emphasis on postpartum depression either before or after the birth. Very few women had someone sit down and review resources or information with them.

When asked if they had attended prenatal classes, several women reported that they had gone to at least one class, but the majority had not. The topics of the classes varied widely and included:

- Prenatal/pregnancy care
- ♦ Diabetes education peer group
- ♦ Birthing
- ♦ Hospital tours
- ♦ Breastfeeding

- ◆ CPR
- ♦ Newborn/infant care
- ♦ Caring for premature babies
- ♦ Car seat installation

The value of the classes to participants also varied widely; some learned a lot, and some very little.

It was enlightening. It was updated information from what I thought I knew because it's always good to learn new techniques and things to being a mother. - Tyler

I took one class for breastfeeding because I wanted to – my goal was to nurse the baby for six weeks, but the other classes, they didn't offer me any free classes. I didn't want to pay for them. – San Antonio

Yes, I definitely would have attended a parenting class because I had my first at 16. So, I was just a new teenager. I was still in school. As far as delivery and birth and stuff, I just seen the basics in health classes and stuff. If I had went to a parenting class, that would have been very informative to me on how to deal with the new stress of having a baby and the afterbirth. - Tyler

A number of women reported that they had barriers to attending classes or would have been interested, but were not offered any. Barriers included scheduling and work commitments, transportation, and costs. Some women did not want to attend a class because they felt like they knew what to do from prior children, family, instinct, or other sources (e.g., birthing videos/shows such as *A Baby Story*). Others were just not interested at all.

I didn't go to my classes because I work mostly in the afternoon, and I had morning shift. ...Whatever questions I had, I asked my mom. – Laredo

The prenatal classes and the nursing classes were in the mornings. Since I was already missing a lot of work, I couldn't take off to take the classes. I did my own research on the internet. – San Antonio

All classes offered took place in English, even in clinics with a significant base of Spanish-speaking patients. However, the Spanish-speaking focus group participants did not report this as a significant barrier as they were used to receiving healthcare primarily in English.

Participants made other preparations for the birth and the arrival of their babies by packing hospital bags as well as getting baby clothes, bedrooms, supplies, and other items ready. Very few women in the focus groups had a set birth plan or knew what that was; those who did have a plan noted only that it included who they did or did not want in the delivery room and was not specific to their medical conditions. Many of the women, however, had planned C-sections or inductions due to their conditions.

# **Hospital Birth Experiences**

When asked how prepared they felt for the birth experience given their conditions, participants had mixed responses. Some had spoken in depth with their healthcare provider(s) and knew what to expect or what may happen during the birth process and in the hospital as well as any potential risks at that time. Some women had knowledge from their prior babies and births that helped them to feel prepared. Many, however, felt unprepared for what happened in the hospital or during their baby's birth. In some cases, this was due to the fact that health challenges arose for the first time as a surprise during the birth process (e.g., birth started prematurely, hemorrhaging, or a breech baby flipped into position late and a C-section was cancelled for a vaginal birth). In other cases, participants felt that their providers had not fully informed them about what may happen with their condition or in general in the hospital and birth process.

I wish my last one my doctor would've informed me a little bit more on — they had to induce me, which that was horrible. That was a horrible experience. If they would've told me a little bit more what to expect. —Beaumont

They didn't tell me that I was at high risk for a C-section. I was unprepared and to get there and to be thrown off like, "You have to have a C-section." I was mad. - Dallas

As a result, participants also had mixed opinions on how things went in the hospital, including with their medical care. Several women reported feeling scared in the hospital, especially when things escalated quickly during their birth experience.

It went badly for me. I went to the doctor. It was a normal appointment. I had my little boy with me. My pressure was so high they said, "We're going to the hospital now." In the building where I was in the hospital, there was a tunnel that we had to go through. They took me through the tunnel practically running. – San Antonio

It was a C-section. They gave me the epidural and I started trembling a lot. In the middle of the delivery, I felt everything. I felt a lot of pain and I started screaming. Then, I don't know how, but I saw this blood spurting out. The doctor said that he thought I was going to die. – San Antonio

Most participants did not receive information specific to their conditions at the hospital. The majority reported receiving general information on how to stay healthy and prevent further complications and identify risks upon going home. In a few cases, women left with specific discharge instructions or equipment. A number of women talked about getting a large folder or packet of information and resources. In just a few cases did someone sit and review the information with a participant. More often,

women were left to review the information on their own and, admittedly, some discarded or never reviewed it.

They give you about the Social Security, the information. They give you the pamphlets all over again – how to take care of the baby, how to shower, the breastfeeding. They emphasize that a lot. The postpartum depression. –Laredo

*They give you a big folder.* - Laredo

A folder full of brochures that explain to you if you need to back to the hospital or when something is an emergency if you're bleeding or something like that. – San Antonio

### **Postpartum Care and Experiences**

The overwhelming majority of women felt that their postpartum visits with providers were too brief and not particularly helpful. Facilitators and participants discussed postpartum care and experiences in each focus group, including provider visits, medical care specific to special health conditions, experiences and support with a newborn, and women's confidence levels regarding longer-term health and medical care.

The majority of women – though not all – went to at least one postpartum visit with their OB/GYN. This was typically six weeks following the birth, but sometimes sooner for women who had special conditions or equipment to check or remove. Participants cited insurance limitations (i.e., they were told or understood that insurance would only pay for one postpartum visit) as reasons for not going to more than one postpartum visit. The few women who did not attend any postpartum visits cited lack of transportation or moving to a new city, not identifying a provider, or not having time because of work as the reasons why.

Nearly all participants noted that their postpartum visit was very fast and that they didn't feel like they had enough time with their providers to ask questions and discuss their own health needs and next steps even though they had a high-risk pregnancy and ongoing symptoms. For some, they were left wondering if and when the high-risk health condition that emerged during pregnancy would subside.

It was very fast. I think I was a lot longer waiting in the waiting room than with the doctor. – San Antonio

I lost 20 pounds in two weeks, and I wasn't even eating. I was breastfeeding, so [the doctor] didn't address that. I was just worried about the baby. I was almost wasting away. I got my weight back eventually, but I lost a lot of weight really fast. – Beaumont

I went to a two-week postpartum and the six-week postpartum, but I also had to go to another doctor because five days after we went home, I'm trying to breastfeed, I couldn't breathe. Laying on my back, I couldn't breathe. I had to go to a doctor, and they found out that they gave me too much fluid. I had fluid on my heart and lungs. I had to go to a heart specialist. - Dallas

It was a very quick visit. I was already dealing mastitis. I had what they call a milk blister. It was recurring mastitis. I had it four times in three months. He kept saying, "You're fine. You're fine." I'm going, "No, I'm not. I'm getting sick, frequently, and I'm exhausted." It felt like a lighter to me, 24 hours a day, literally, like I was on fire. I wish he had listened and not just rushed me through the appointment when I had concerns.

- Tyler

During the postpartum visits, participants and their providers often discussed birth control options (medications, implants, and getting "tubes tied") as well as postpartum depression symptoms. Some women also discussed the following with providers: ongoing monitoring of special health conditions; letting their body recover before getting pregnant again; breastfeeding; and safe sleep practices. The majority of women in the groups were aware of public health recommendations against bed sharing, to put babies to sleep on their backs, and to keep cribs clear of stuffed animals and extra bedding. Some talked about co-sleeping anyway, especially when breastfeeding/feeding in the middle of the night.

When asked what she wished her provider had told her in the postpartum period, one woman responded:

Definitely how to control stuff, like high blood pressure, for lifelong. I think if they would have given me more information then I wouldn't be having so much trouble with it now.

- Tyler

Participants wished that their providers had asked them the following types of questions.

Do you feel:

- ♦ Safe?
- Overwhelmed?
- Sad? Depressed? Crying for no reason?
- ♦ Dizzy?

# **Newborn Care and Experiences**

Like many mothers of newborns, several of the participants were stressed or overwhelmed when adjusting to life with their new baby while also recovering from the birth. This was especially true for those who were juggling the care of a newborn and themselves and their other children, which was a common theme in these focus groups. Some women felt as if all of the focus was on their babies and not on their own health or concerns.

I don't care how many babies you have, it just seems like you're a first-time mom all over again with each kid. -Dallas

Additionally, recovery from difficult birth experiences exacerbated the challenge. Some women were attending to infections or injuries, told to rest for longer than average, or taking care of premature babies or their own special equipment.

Yes, with me, they definitely told me, with my high blood pressure and preeclampsia and all that, to really take it easy and not work 12 weeks after. - Tyler

In Laredo and in San Antonio, where the participants were largely Hispanic women, they bemoaned the lack of opportunity to practice the cuarentena, which is a cultural tradition of allowing a new mother 40 days to rest and abstain from housework, cooking, caretaking, chores, and sex following the birth of a baby. Several women in the groups practiced this tradition to some extent, though many not fully due to their own desire to be active as well as family and work demands.

I know that my mother told me that it's very important for you to not do all those things because there's some air that goes into you and you could die. I don't know how you could die, but I guess she says because you're very sensitive to everything at the moment. You have to wait those 40 days to recover. - Laredo

# **Postpartum Depression and Ongoing Conditions**

Participants were asked how much support and information they were given for their health conditions in the postpartum period, including how to stay healthy and prevent future complications. Their responses were mixed; several women felt that they had adequate care and guidance, while others reported getting no guidance or only minimal instructions for ongoing healthcare. In a number of cases, women were told to continue to monitor their health conditions and symptoms or to continue taking a supplement or medication. In some cases, providers did not follow up on referrals or with ongoing care; in other cases, women were instructed to follow up and did not.

The following quotes are examples of the ongoing instructions women received from providers during their postpartum visits on what to do or what to expect.

*Expect to be sad.* –Tyler

They just say to just take care of yourself, like all of your – the diet they give you. That's about it. "Take your pills." – Laredo

My gynecologist told me... "Every six months check your blood to see if your levels are all okay still." Obviously, the insurance is not going to cover any of that. I keep going every year because of the cost. – San Antonio

My OB/GYN actually really did give me a lot of -I'm going to say he awakened me to better eating habits and things that you can do. - Dallas

My little girl came home on oxygen. They still had a small feeding tube put in, for about two weeks after she came home. They didn't tell me how to clean it. I really had to go to Google and learn how to do it. - Tyler

Multiple women in every focus group mentioned challenges with postpartum depression symptoms and, unlike other health conditions, they reported being especially reluctant to tell family members, friends, and providers about their struggles at first – even if asked directly. Several women were caught off guard or embarrassed by their symptoms.

I wasn't familiar with what anxiety and depression was, so I didn't know that was actually the issue that I had. It wasn't until other things happened and then you put a label and then now you know what's going on. I wish that it would've been a part of the classes, that actually this is something normal that women experience. – Beaumont

As mentioned previously, some women were dissuaded from taking mental health symptoms seriously by family members or even providers or had friends or family members encourage them to "be strong" and handle the challenges on their own. At least one woman mentioned that her postpartum symptoms did not emerge until a few months after the baby was born, making it difficult for her to access her providers for care as she no longer had insurance coverage.

# **Breastfeeding**

Participants had a wide range of breastfeeding experiences, and the majority of them attempted to breastfeed for some period of time. The women in the groups breastfed anywhere from a few days to a few weeks to a few months to many months. This included pumping and, in some cases, formula supplementation. A few never intended to breastfeed at all due to a lack of interest or confusion about if they could, given their medications or conditions. Some reported that health challenges in the early hours and days following the birth prevented them from attempting to breastfeed or resulted in their babies receiving formula without their consent (e.g., infant in the NICU, mother on medication following a surgery and told not to breastfeed, mother's recovery from a challenging birth experience).

A number of women recalled a visit from a lactation consultant while in the hospital. When faced with a breastfeeding challenge, some followed up with that lactation consultant or with another one (e.g., through WIC) or sought help from family members or their OB/GYNs.

[The lactation consultant] actually gave me her phone number, and she said, "I'm available anytime. If you have problems, I can go to your house." – Laredo

She's screaming and they just handed me a baby. I didn't know how to make the baby latch on. She screamed for like 20 minutes nonstop, just, "Ahh!" I'm like, "What's wrong with this baby?" When she did latch on, oh, it hurt. – Beaumont

I wanted to nurse him, but they wouldn't let me because they had me on morphine.

- San Antonio

When asked about the help they requested and received for breastfeeding, women also reported the following:

Participant: I told my mom. I said, "Mom, is this normal? Do all babies need to get breastfed?" They're like, "No, not really." I said, "It hurts. Why does it hurt?" She's like, "Because you have a lot of milk that you need to get rid of." I had to go to the doctor. I told him what was happening."

Moderator: *Did he help you?* 

Participant: Yeah, he gave me a pamphlet.

- Laredo

When the group in Tyler was asked what they did when they had a breastfeeding challenge and who or where they turned to, their answers included:

Dr. Google.

*I called the Lord.* 

I talked to the lactation specialist at the hospital when I was there. Then I also did the one from the WIC office.

I called my OB.

My mama

#### **Future Health and Care**

The focus group moderators also led participants in a discussion about their ongoing health and healthcare. This included talking about their ongoing concerns, which typically were connected to birth control, future pregnancies, or their health condition(s).

Nearly all of the women in the groups felt confident that they could explain their pregnancy/birth experiences and conditions to a new provider and identify warning signs in the future. Additionally, nearly all of the participants said that they would feel comfortable speaking up – asking more in-depth questions and for more support – if they were to go to a new doctor or get pregnant again.

When I got pregnant the second time, I said, "I don't want to go back to [that provider]. I don't because she was rude." After that, I talked to my [new] doctor that I've had, and I said, "Before we even start, I need to know that you're on my side and you're going to listen to my concerns." I felt comfortable speaking up after that because I didn't like the way I was treated the first time. - Tyler

However, not all of the participants were confident that their health conditions were currently under control or knew what their future health needs would be.

Honestly, I hope that the anxiety will go away because my anxiety is directly linked to my blood pressure issues. I thought that after I had the baby and my body regulated, that everything would resolve. – Beaumont

Before I have another baby, I need to be in a better place, overall, mentally. - Tyler

#### Health Education and Media Use

Women receive health guidance, messages, and information from a variety of sources. As previously discussed, they often go to trusted family members, partners, and friends with health questions, when facing a health challenge, or when diagnosed with a health condition or risk. They also often turn to media sources, especially the internet and social media, for answers.

Participants reported that they frequently use the following media and internet sources:

- ♦ Google
- Apps (e.g., to track pregnancy progress, baby growth, or for peer consultation/Q&A)
- Links provided by healthcare provider or within resources they have received
- ♦ WebMD
- ◆ Facebook and Facebook groups (e.g., for first time moms or a local mothers' group)
- ♦ YouTube
- ♦ Books
- ◆ Instagram

[Your providers] tell you something and then right away you go and check it out on the internet. – San Antonio

I don't remember the name of it, but you put your question in and lots of people will put their opinions and their comments. It's somebody else just like me who's going through the same experience. I really trust that. – San Antonio

#### Some recognize the internet's limitations:

I stopped reading all that stuff [on the internet] because I started getting really scared of all the things that can possibly happen. – San Antonio

In addition to media and internet sources, some participants also appreciated opportunities for connection and camaraderie with other women, especially those who had had similar experiences.

Not just on Facebook, but maybe some real-life mom groups, where moms meet, who's had kids, like ...who just has kids previously, especially for the high-risk pregnancies and stuff because I think that would've been a lot of help because I had friends, but they wasn't pregnant. - Tyler

# **Health Messaging Ideas**

When asked where they would like to see or receive health information, messages, flyers, and other resources outside of their healthcare providers' offices (e.g., OB/GYN, primary care doctor, pediatrician's office), participants suggested:

- ♦ HEB, Walmart, and Target
- ♦ Baby section at the pharmacy
- ♦ In a free clinic
- Medicaid, SNAP, and WIC offices
- ♦ Schools
- ♦ Facebook/social media
- Through an app
- ♦ A resource with links for online information
- A resource with a phone number too to be able to talk to a person

<u>Text Message Outreach:</u> A few participants also discussed the value of receiving text message check ins, possibly with links to additional resources or links to a class schedule, with reminders, and/or with positive affirmations too.

I would love to get [words of encouragement], at least, just randomly. When you're not expecting it and you're about to cry, you get a text. - Tyler

Maybe in a message for the class schedule, if there's a link thing, just say, "If you're interested, click on this link." That way, it's not something that you're having to read through. - Tyler

Participants had the following additional ideas on how to better and more strategically reach women like themselves with health messages and some of the materials tested in the section below.

If this is information they're giving parents [in the hospital], don't give it to them when they're walking out. Maybe, perhaps, when they take the children for 30 minutes to bathe the babies or whatever, or when they bring the dinner to the mom or something. "Here's a book that we'd like for you to look at. Maybe you can take a look at it and see what you think." Ask them afterwards about it. - San Antonio

With my OB, in the lobby, they have two screens. Then they have a bunch of bulletins. In those screens, they start explaining to you the Zika vaccine, the flu vaccine, the postpartum depression, the SIDS, the glucose testing. It's like one of those keychains but in a presentation. While you're waiting, ...you're reading. That's awesome - Laredo

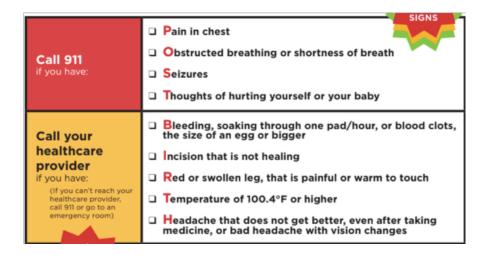
### **Materials Testing**

Focus group participants reviewed multiple materials and resources intended for mothers of newborns to assess what format and style would by most engaging as well as what key information was most important to them. The AWHONN flyer and the Texas Department of State Health Services *Information for Parents of Newborns* booklet were tested in all locations. The *Bright Futures* booklet and *Loving Support* keychain were tested in Laredo, Dallas, San Antonio, and Tyler. One additional intervention example – a charm bracelet – was tested in Tyler and is discussed below. Descriptions and images of all of the materials tested can be found in the Materials Descriptions section of this report.

#### **AWHONN flyer**

Focus group participants overwhelmingly liked this resource. While several believed that they had received similar information within a larger packet of information, they appreciated that this was a one-page flyer that was simple, clear, and to the point. They liked that it was attention-getting, honest, and had practical information as well as examples. Several women said that they would put it on their refrigerators, and many women said that it would be good to share with partners and other family members so that they would know the warning signs as well. A few women also noted that they would take a photo of the flyer to store on their phones for reference.

What I like about it is it's quick. ...it's something you can look at pretty fast versus the packet that you get. The packet is papers and you've got to read. This, I can read this real quick. – Beaumont



If you put it on your icebox and your partner, whoever may be home, that they can know these signs, too. Sometimes you're too busy with the baby and you don't notice these things, but if someone else can see it in you and recognize it. – Beaumont

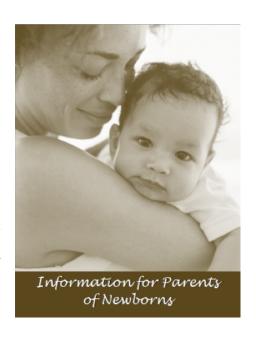
The big "save your life" in the corner. It got me interested on what it was talking about. - Dallas

I literally threw that [big packet of] stuff away [from the hospital], but this is something I might keep. - Tyler

#### **Texas DSHS Information for Parents of Newborns**

While women in Texas typically receive this booklet during their hospital stays, only some of the focus group participants remember seeing or receiving this resource.

Participants appreciated the wealth of information included in this booklet, but they did not find its style or format engaging overall and had a number of ideas for improvement. Multiple women said that it looks like it is for first-time moms only. They believed that it was too long with too much text per page, too big, and not attractive. They had the following specific suggestions:



- Add color
- More bullet points, pictures, and charts/diagrams
- Add color-coded tabs on the side by section

While some women felt that the information was not well organized and could be streamlined and re-ordered, there was no clear consensus about a new order of topics. Some women suggested that caring for infants and SIDS information be up front. A few women also suggested that there be more information or resources on adjusting to more than one child as well as on what to do if you have a child with special needs (e.g., caring for preemies, developmental red flags and signs to look for).

[I] especially wanted more information with children with special needs because that's just like a little page with a little information at the last. Especially my son, being autistic and ADHD, I would like to have more information about that, like the signs. – Tyler

Several participants noted that they specifically liked content or elements such as the immunization chart, the charts and checklists and callout boxes in general, the "When Baby Cries" section and callout boxes/charts, the "Postpartum Mood Disorders" section and the SIDS and safe sleep information.

You get that from the hospital, but we don't pay attention to it because it's a book.

- Beaumont

I think it looks really dull. I'm a book reader. I love to read, but this is just – it just looks boring. – Tyler

Some smiling babies. This baby's not even smiling. - Beaumont

It's sad. - Dallas

It's a lot of information for someone who hasn't slept well. I feel like you don't have the time to read all of that. Or, you're half asleep. It's a lot of text. – San Antonio

#### **Bright Futures Pocket Guide**

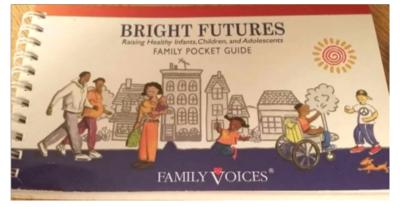
This was the overwhelming favorite for these participants across all focus groups. In contrast to the larger booklet, participants liked its size, convenience, bright colors/images, and color coding throughout. A number of women said that they would be likely to put it in their purses or diaper bags as a reference item to pull out when needed, perhaps in the pediatrician's waiting room as a way to spark questions to ask during the visit or when they had a specific question or concern. A few women did note that the text was too small for them in some places, but overall, there was a positive response to this item.

This appeals to me much more. Yes. As soon as you gave it to me. - San Antonio

The sections are well defined. It's like an index. On the side it tells you. It's color-coded

and it tells you what's in each of the sections. It tells you, when have the baby right away and if you want to know something about breastfeeding you're going to find it right away. There it is. – San Antonio

You can carry it in your purse, in your diaper bag. – Laredo



#### **Loving Support Keychain**

Some of the women liked this format and several reported having seen or received this or a similar item in a pregnancy or breastfeeding resources bag from WIC. Those who liked it appreciated the simplicity and colors on this item as well as the brief tips. However, many participants felt neutral about or did not particularly like this item or format; only a few women liked it better than the *Bright Futures* booklet.



I'm just being totally honest here. I kind of think it's cute. It's a good idea. I get, in theory, it's a good idea, but I'd rather just Google myself the problem than look at a website, try to type it in. - Tyler

I think I wouldn't use it because it's more work. You're going to look for it and then you're going to have the children over here and your newborn. It seems like more work. Less convenient, yes. [With the

other booklets] whatever I'm looking for is right here. - San Antonio

I like things like this because I use them for multiple uses. I would keep the information. I would refer back to it. Me, personally, I'd put it on my keychain to keep it around. -Tyler

#### baby gooroo Charm Bracelet

In Tyler, this breastfeeding charm bracelet was tested as a possible intervention for women at high risk and as a method to incentivize them to attend prenatal and postpartum visits as well as motivate them to engage in specific health behaviors/activities. For example, women could earn a charm each for attending a nutrition class, breastfeeding class, and an infant care class.







All of the following quotes are from the Tyler focus group. Participants had very positive feedback on this item.

These are adorable. They're beautiful.

Yeah, because I feel like, when I would get a charm, I'd feel accomplished, like I actually did something. It would be like to an AA meeting and getting your three-year chip. That's how I'd feel.

I think those are good key words that new moms need to hear.

Positive reinforcement, tangibly. I like that.

#### Conclusion

Across the board, the women with high-risk pregnancies in these focus groups often did not feel as if they had received the information, preparation, support, and follow up they needed to understand and effectively manage their risks and conditions during pregnancy and birth as well as in the postpartum period. These women experienced a range of high-risk symptoms and medical or mental health conditions that presented prior to pregnancy, during pregnancy, during the birth experience, or in the postpartum period. While some participants reported that they had a good rapport with their healthcare providers, many did not have that rapport or simply not enough time to develop it or ask questions – they either felt rushed, dismissed, or didn't even know what ask during visits. In some cases, cultural or family influences (e.g., "stay strong" "take care of things yourself") or other non-health factors (e.g., caring for other children, work demands, lack of insurance) prevented them from seeking or receiving more professional support.

Most participants did receive ongoing prenatal care, sometimes specialist visits, and at least one postpartum provider visit, so they were in regular interactions with healthcare providers. Fewer than half of participants attended any sort of prenatal education class and the subject matter varied widely for those that did (e.g., breastfeeding, hospital tours, infant care, gestational diabetes, car seat installation) and rarely was about the preparing for birth itself or managing health; barriers included scheduling with work or childcare commitments as well as costs or not knowing any classes were available.

While nearly all of the women received some type of educational resource (usually print handouts or booklets) at some point in the prenatal period and when leaving the hospital, – and searched out their own answers online or by asking family/friends – participants were eager to learn more in the context of trusted relationships and conversations with healthcare providers (including hospital staff and experts who may moderate online forums) and peers/other mothers who have experienced challenges. They felt that this additional personal support would have made things less overwhelming during pregnancy and postpartum. Given the challenges they experienced, most participants feel better equipped to advocate for their needs now, but a number of them still don't feel as if they know how to manage and maintain their health in an ongoing way or in regard to a future pregnancy.

# **Preconception Men**

#### **Participants**

SUMA conducted two focus groups with young men who do not have children in the fall of 2018. Table 4 offers a summary of the participants.

Table 4: Participants (N = 22)

Location	Participants
Amarillo	12
Dallas	10

# **Lines of Inquiry**

The interview guide for the two focus groups is included in the Appendix. The lines of inquiry included:

- Priority health concerns and health-seeking behaviors, including typical and trusted sources of information
- Use of and experiences with healthcare and healthcare providers
- Barriers and attitudes about healthcare
- Review and feedback on health resource materials as well as media use/habits

### **Detailed Findings**

# **Priority Health Concerns**

In an opening exercise, as described in the Methodology section, participants chose an image that represents to them where they are in their lives. Some men spoke about feeling enthusiastic about their futures and careers. Other men shared that they feel anxious about transitions in their lives, such as losing jobs.

I picked the fair or a carnival because I'm like a stage of excitement, like a party about to blow up. – Dallas

I have little kids all running in a circle. I've been low on income in the past couple months, but my friends help me through a lot of stuff. I'd say like a close group.

-Amarillo

When asked what their top of mind health concerns are, men listed the following:

- STDs and STD prevention
- Injuries from working manual jobs, hernias, and back problems
- Physical checkups
- Healthcare costs and access
- Drug and alcohol addictions and overdoses
- Afraid of finding out they have a health issue when they go to the doctor
- Not being able to have children
- Heart attack

- Diabetes
- Obesity
- Mental health, including depression, anxiety, OCD, PTSD, and bipolar disorder
- Suicide
- Acid reflux
- Balding
- Dental care
- Self love and self esteem
- Cancer

Participants were then asked what they do to address their health concerns. For sexual health concerns, men said they use condoms, limit their number of sex partners, and get tested for STDs. To address mental health issues, such as depression, most men said they try to talk to or go out with trusted friends and engage in activities like playing music. To prevent workplace injuries, a few men said they follow procedures and try to lift items correctly.

Many men said they talk to their mothers about their health concerns. Some men said that their fathers or other male family members are more likely to brush off health concerns so they are not the person they typically talk to about those issues. Those men went on to explain that their fathers tended to ignore health issues and rely on home treatments rather than doctors themselves. Those participants also mentioned that they felt like having access to Google and social media helps them be more aware of health concerns and treatment as compared to their fathers.

They just weren't very aware. Back then, they weren't very well educated. They'd just be like, "That's the way God wanted it, to lose a foot." "No, bro, you should have washed that infected foot. You would have been great." – Dallas

Some men said they talk to friends and their partners. Participants reported that conversations with partners around health are typically around STDs and sexual health topics.

When asked what prevents them from addressing their health concerns or talking to healthcare providers, several men brought up not being able to afford the costs of doctor's visits – or of quality providers. Some men said that not wanting to wear condoms and not always knowing the STD status of their sex partners can be a barrier for them practicing safe sex specifically.

For mental health, a psychiatrist, but they're expensive. If you want a good one, you have to have really good insurance. I don't have good insurance in my job, so I usually get the free clinics or whatever, and they treat you like a piece of cattle. They just get you in and out, because you're not able to actually pay them. They also don't provide you with the right kind of medicine. It's not the best kind. –Amarillo

Participant 1: No, we ignored it. Just don't get sick.

Participant 2: Yeah, it's an inconvenience. If you decide to go actually seek treatment, that's an expense. Might as well self-treat it at home.

-Dallas

# **Accessing Healthcare and Annual Physicals**

Participants who had gone to a health professional in the past year did so for one or more of the following reasons:

- STD testing
- Workplace injury
- Asthma attack (urgent care)
- Chest pain (ER)
- Physical
- Check ups

- Car accident (ER)
- Physical therapy
- Fever
- Seizures
- Mental health symptoms

Overall, the only preventative care participants receive is STD testing and, for very few, an occasional check-up or physical. None of the men in Amarillo currently had a doctor identified. Most of them had no health insurance. Most participants agreed that they only go to the doctor if something is seriously wrong; again, the primary barrier is costs.

For me, it was just a physical. Other than that, thankfully, no. If you're staying healthy, you know this. I don't go there to visit the doctor. Other than that, no. – Dallas

I just think that insurance is a problem for a lot of guys because we live in a really messed-up American healthcare system. If your deductible is \$7,000 and you don't get any coverage until you meet the deductible, then you're effectively screwed. Congratulations, you're paying \$120 a month for it, or more. I think that's a major problem that the cost of healthcare – there are no effective price controls on healthcare. –Dallas

When moderators asked what men think of when they hear the phrase "annual physical" or wellness exam, most said that they think of a sports physical. Participants said they would expect doctors to check their reflexes, heart, lungs, vision, blood pressure, and heart rate at an annual physical. Some participants had had one in the past year, while others said they had not had a well check since they were younger, in high school playing sports or were on a parent's insurance. When asked why they had not had a wellness exam in the past year, participants reiterated that they do not have the time or money to go to the doctor, especially if they feel well. Some worried about having to take off work to go a wellness exam.

I feel healthy. I'm just like when a problem comes, I will go to the doctor. Until then, I'm just like why take the time out of your day to do that? – Dallas

When asked where they could go to schedule an annual physical in their community if they did want one, some men knew of free or walk-in clinics that were options. A few of the men said they would ask their mom where to go, and some said they would use Google to find a doctor. The few participants with health insurance said they would have to call their insurance to find an in-network doctor first. Participants said they would want to know how much it would cost, how long it would take, and see reviews of the doctor before booking an appointment.

[A wellness exam could take] two hours because you're waiting on a doctor. If he's not ready to do it, then you have to wait until he's ready, even though you're ready to do it. -Dallas

You're like screw this system. That's why you have individuals who do not go to get physicals because the healthcare – it makes sense. Would you like to be whacked with a \$500 bill? – Dallas

#### **Sources of Health Information**

Moderators then asked men how they learn how to stay healthy or manage symptoms that arise. Participants said they get this information online, either through Google, YouTube, or social media platforms. Several men said they will Google their symptoms if they are feeling unwell. Many men shared that they learn healthy eating and exercise habits by following certain YouTube channels, Facebook groups, and Instagram accounts.

Participant 1: YouTube subscribers. I subscribed to a lot. They teach me what to eat, how to exercise, stuff like that.

Participant 2: On Facebook, there are groups that I'll join in on my feed and post stuff that's going on.

Participant 3: Facebook is a big help.

Participant 4: Instagram. I follow a lot of people, kind of what he was saying, that show you what to do, how to do it, what to eat. Social media. It's everywhere now.

-Amarillo

When asked if they would like to receive information about getting a physical through their Instagram feed, several men said they would be initially skeptical, and would want to check out the source behind the post to make sure it was not a scam. One participant also wondered if such an ad would be able to offer specific pricing information that would apply to him and his local doctors.

You're saying if it's on Instagram, they're just showing you this standard price and stuff like that, or are you saying that — because I think it depends on the person because everyone has, probably, different insurance plans. Some could be paying more than others or less. Maybe that's a good standard to go off of, but you shouldn't hold your hopes up too... because there's average prices. There's also a low end and a high end of that. It really depends on where you fall in that. — Dallas

# Reproductive Health - STDs and Birth Control

When discussing STDs specifically, men in the groups reported that they receive information from friends, family, doctors, and school. Some, however, pointed out that their schools did not educate them well on the topic. Several men spoke about having conversations with sex partners about STD testing at the beginning of relationships.

Participant 1: School didn't necessarily tell you if you have something like, "These are the things to look out for if you do have unprotected sex." Because they don't want you to. They already assume that you're not going to and, if you do, you need to go to the clinic.

Participant 2: They pretty much say, "Be protected." They don't tell you the stuff that's going to happen afterwards.

-Amarillo

When asked what they knew about birth control methods, most men were familiar with multiple methods, including IUDs, Nexplanon, vasectomy, NuvaRing, Plan B, condom, female condom, and birth control pills. Men demonstrated familiarity with the mechanics of various birth control methods, though many were skeptical of the effectiveness of birth control pills at preventing pregnancy. Participants said they hear about birth control methods from friends, partners, and TV commercials. A few participants shared that they use multiple methods of birth control, such as birth control pills and condoms, for additional protection against pregnancy. A few men in Dallas noted that seeing friends their age having children influences them to use birth control methods.

My last girlfriend, we were together for a couple of years. She was older than me, but she had an IUD. It's that T-shaped thing or whatever. They implant it and it stays in there for five years, and it makes her body think that it's already pregnant, so she does not get menstrual cycles, doesn't really get the PMS symptoms. Once you guys trust each other and you know you're both healthy, it's just a free-for-all. That really makes it more enjoyable, so I do enjoy it. I did have a girlfriend who was on the pill and she was very irresponsible in forgetting to take it at times. Whenever she'd forget for a day, she would start her period again, so she's getting three or four a month. It would screw her all up and that wasn't very fun. I did meet another girl. She had that implant [in her arm]. I'm not sure what it was supposed to do, but that was just gross. I didn't like it. – Amarillo

It's crazy. Growing up, all my friends back home have kids at a super young age. I'm like, "How do you all keep having — do you not pull out?" I just realized most of the girls I've talked to are on birth control. I think girls who are in college, for the most part — some of them are dumb, but most of them are — they try to be responsible. I guess the education level determines how protective you want to be of yourself and your financial future. —Dallas

#### Online and Traditional Media Use

Moderators asked participants about their media and social media habits. Men mostly reported that they get online on their phones rather than on laptops. While several participants had access to laptops, they said they only used them for school and use their phones much more frequently.

Participant 1: *I hardly know any people with laptops anymore.* 

Participant 2: The only time I use a laptop is for school.

Participant 3: *If you're not school, you don't need a computer.* 

Participant 4: Even a tablet does more than a computer does nowadays. There's really no need for them.

-Amarillo

Many men said that they use social media platforms, including Facebook, Twitter, and Snapchat. A few said they use LinkedIn and Reddit too. Participants agreed that social media is the best way to reach them with messages, since that is where they spend a significant amount of their time.

Several participants said they listen to local radio stations. Many men listen to online music streaming services as well, such as Spotify, Pandora, Apple Music, and SoundCloud.

Aside from watching sports, most men in the groups said they do not watch broadcast or cable TV, but instead use streaming services such as Netflix, Hulu, YouTube, and Amazon Prime. Only a few participants said they have cable in their homes.

Some men reported that they use health-related apps too, including NikePlus and MyFitnessPal. A few had either Fitbits or smart watches that they use to monitor their health.

# **Materials Testing**

Participants in each focus group had the opportunity to review and give feedback on multiple health promotion and educational resources, discussing how appealing and engaging each one was for young men like themselves. More information on the individual resources can be found in the Materials Descriptions section.

Bedsider Birth Control Pamphlets: Men generally liked these materials. Several pointed out that they liked the fact that the pamphlets direct them to a website so they could

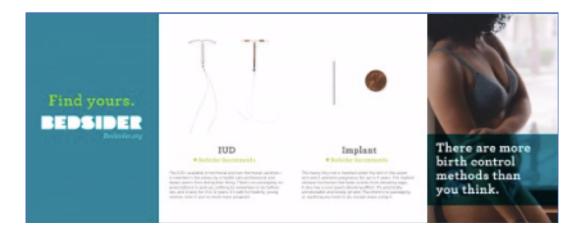
learn more. All participants in Amarillo said they would visit Bedsider.com after looking at the pamphlets. Participants found them informative and concise.

Participant 1: It's got all this stuff that you need to know. It's better than reading a textbook.

Participant 2: I was going to say it's informative.

Participant 3: *I like the images. The images are great.* 

-Dallas



Some participants noted that they were thrown off by the images selected to represent different birth control methods, such as a log and a corkscrew, though all participants in Amarillo said the information was clear to them. Some also had questions about what the "party ready" label meant. Some in Dallas wished that there was more of an explanation on what each method is and how effective it is.

[I liked] who liked what or why they would purchase over another one, so when you and your girlfriend talk about birth control, you guys know of other people's opinions which ones to stick with and which ones to stay away from... Yeah different reviews of different things. If you hear one guy say that it causes his girlfriend to go through PMS every week, then you'd probably want to stay away from that one. – Amarillo

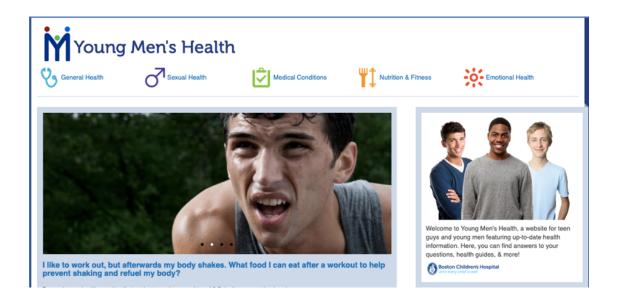
<u>Text Message Campaign</u>: Several men responded favorably to the idea of signing up to receive texts about men's health. They liked the sample messages about where to get free condoms and about reducing stress through exercise. Participants also said they would want to receive messages about mental health and eating healthier. Several participants agreed that receiving texts twice a month would be a good frequency, while a few said that would be too often and that once a month would be better.

<u>Young Men's Health Site</u>: Men overall liked this website, noting that it is well organized by health topics that interest them. Some men made note of the information on emotional health, saying that they appreciated seeing that topic being addressed.

It's a good website. It tells you one-by-one when it comes to the STDs exactly: symptoms, what to expect, people who most have it. I like it. – Amarillo

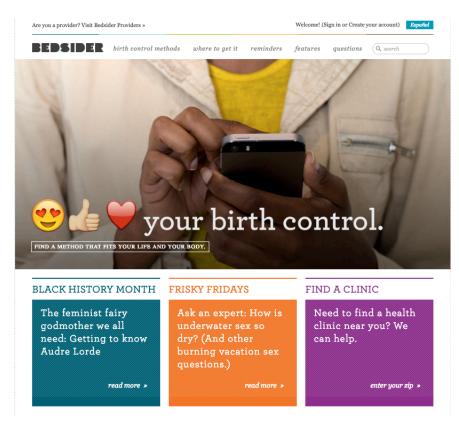
I like it, because once you click on the page, everything's right there. You don't have to scroll anything on the side. The mental health and the general health and the sex part, it's all just right there...Then, once you click on one, they break it down to what there is.

-Amarillo



<u>ShowYourLoveToday.com</u>: Many participants felt that this site was geared towards women because of the photos and heart icons, and they did not find it compelling. They said that, compared to the Young Men's Health Site, this site is not as clearly organized.

Bedsider.com: This site was well liked by most men in these focus groups. Participants said that they liked the large images and interesting topics organized more like a social media newsfeed where they could scroll through various articles without having to do a lot of clicking. Men gave more thorough feedback on this site compared to the others and explored more of the site's articles. Men in both locations pointed out that they liked that the site is not solely about sexual health, and that it seems targeted to young people like themselves.



It's a variety of topics, but it's all up front. With the others you had to scroll through it and click on four different links to find it, but it gives you all the interesting articles, just ready on the front page. – Dallas

Participant 1: *I like the words they use. I can relate to it, the way I talk.* 

Participant 2: It's easy to use... You know they're more pointing to our age.

Participant 3: It's not entirely about sex or condoms or birth control, because there's one of those that says, "Six things you can do when you want to scream." It's really informative about general information.

- Amarillo

I think it is really interesting for all of us, "What to do when you run out of condoms." I think that's very important for everybody... I keep seeing stuff I want to read. -Amarillo

I'm on the "Compare Methods" page. That's pretty cool. It gives you a breakdown of – you can put the two side by side – the two that you pick, and gives you effects and side effects [of] the birth control methods. It's looking at the ring and comparing it to the IUD, so which one is better. – Dallas

When asked where men like themselves could or would like receive health information like the resources and materials tested in these focus group, participants suggested at clubs, in Ubers, at concerts or events, at colleges, at pharmacies, or at the mall.

That's exactly what I was thinking whenever I was going through it. I would have to be stationed somewhere, already mind focused on that sort of general health area, like in a doctor's office. If I picked up a pamphlet at the doctor's office, I would be like, "Cool, this is better than the magazine. This has Twitter on it, cool." – Amarillo

### Conclusion

Young men who participated in the focus groups were unlikely to be receiving regular and preventative healthcare. Their main health concerns were around reproductive health topics – STDs and birth control. A few had regular physicals or annual exams. The costs of healthcare and their lack of (or limits in) insurance were barriers to participants seeking out additional healthcare as was the notion that they should only visit a provider when something was wrong. These men overwhelmingly did not have primary care providers and may or may not have known about local clinics and free/low cost healthcare options in their areas.

When asked where they receive or seek out health information, men reported that the internet and their mothers are primary sources. Some might occasionally talk to a good friend about stress in their lives or to their partners. A number of participants reported talking to their partners about sexual health topics, namely to ensure that they were using birth control.

The young men in these groups are frequently online and on their phones, using Facebook, YouTube, and Instagram, including to get diet, exercise, and other wellness information. Beyond watching sports, they use streaming television/movie and music services as opposed to broadcast media.

Of the materials tested, participants preferred the Bedsider website and brochure the best and some also liked the Young Men's Health website. They appreciated resources and information "in their language" and aimed at men (or both men and women).

# **Fathers of Young Children**

## **Participants**

SUMA conducted three focus groups with men ages 18-45 who have a child under age 4 that they live with or share custody of in November 2018. Table 5 offers a summary of the participants.

Table 5: Participants (N = 24)

Location	Participants
San Antonio	8
Laredo (Spanish)	8
Tyler	8

# **Lines of Inquiry**

The interview guide for the three focus groups with fathers of young children is included in the Appendix. The lines of inquiry included:

- Current health concerns, priorities, and behaviors
- ♦ Barriers to healthcare access
- Use of and barriers to accessing preventative care (e.g., annual physicals)
- Experience and participation with prenatal and postpartum care for their most recent child
- ♦ Knowledge, perceptions, and behaviors around pregnancy spacing and birth control/family planning
- ◆ Sources of health information including family and friends as well as resources and media channels
- ♦ Media and social media habits
- A review of sample resource materials in varied formats

### **Detailed Findings**

## Feelings About Health and Health Concerns

As described in the Methodology section, participants were asked to browse through image cards in an opening exercise. Moderators asked the fathers in these groups to select the one image that best illustrated their feelings about their health. Several men said that, since they are young and healthy, they felt positive or not overly concerned with their health. Other men spoke about being aware that they are getting older, or starting to have health issues, and want to maintain their health through diet and exercise. A few men remarked during this activity that they know they should go to get a checkup but have been putting it off.

Mine is, I believe is, a baby bird coming out of the shell. I think of myself, I'm still young, and I consider myself pretty healthy with that, so for that part I consider myself good, but I still have to — I should do some checkups and just [check] everything's fine, but I feel good. — Tyler

I choose the bowl of Fruit Loops cereal. It's kind of no mystery. It's delicious. It's sweet. Sugar is good. My entire family on my dad's side, they're all diabetic. I mean, it's San Antonio. Almost everybody I know has diabetes. I try to keep on my kids, and I try to keep sugary cereals out of the house for the most part. It's hard because every now and then, I want a bowl of Fruit Loops, you know, and so we get a box every now and then. Yeah, but our health is important to try and maintain. - San Antonio

When asked what their top of mind health concerns are, men listed the following:

- Lack of exercise
- Nutrition
- Obesity
- Lack of sleep
- Sexual health/libido
- Sleep apnea

- High blood pressure
- Stress at work
- Mental health
- Diabetes
- Heart issues
- Cancers

Exercise. I really don't do too much exercise. When I was younger, I was always in sports, playing baseball, playing street ball, football, whatever. Nutrition, I really don't do too much on that. I try to take vitamins when I remember to. Mental, I'm working on that, you know. I'm not insane or anything like that, but everyone has their issues.

#### - San Antonio

I worry about being a burden to my kids if something goes wrong. Instead of being the fountain that provides for them. I'll be the burden that they carry. – Laredo

Diet and weight is the biggest one and lack of sleep. If you get enough sleep and your diet and your weight together — exercise, yes, you need it, but I think if you do sleep and diet, you would help your body a little better, and then if you can exercise add it in there, but diet and sleep is, I think, the top two. - Tyler

Several men noted that having a partner that prioritizes health helps them maintain good diet and exercise habits. Some of these participants also brought up that wanting to model healthy behaviors for their children motivates them to eat better and exercise more.

Growing up, I didn't eat a lot of vegetables. My mom would cook it in the rice and the chicken. My wife is used to a vegetable being like a side, like broccoli and carrots. With me, it's always chopped up in the rice and the chicken, you know, so kind of wanting to model that for my kids, I have to get used to eating just a vegetable on the side. My wife helps with that, reading books. - San Antonio

Participants were then asked what they do to address their health concerns. For diet and weight concerns, the fathers shared strategies such as eating smaller portions and preparing meals ahead of time to avoid eating fast food. To address stress, participants said they use physical activity and music. For sexual health concerns, they try to keep the sexual aspect of their relationship with their partner active, and diet and exercise to stay in shape.

Participant 1: Food proportion. Instead of going back for seconds, make your plate and know when you're full to stop. That's what I've been doing the last three to four months and I've lost 20 pounds. Just watch what you eat and stop eating.

Participant 2: Eat small portions every two or three hours instead three big, heavy meals.

Participant 3 Trying to work on meal prepping so you don't get stuck hungry and then you're hitting the fast food.

-Tyler

When asked what prevents them from addressing their health concerns, several of the fathers brought up not being able to afford doctors' visits. Many participants in the groups did not have health insurance. In San Antonio, only two had insurance and, in Laredo, none had health insurance, with several noting that their jobs do not offer insurance. The Tyler participants were more likely to have health insurance, but also brought up that the costs were still too expensive, so they do not go to the doctor if they can avoid it.

Participant 1: I have insurance, but I can't even afford to see the doctor. They take out too much out of my paycheck. The copay is too high.

Participant 2: I don't have any insurance at all. If something hurts, I just have to go to the emergency room or urgent care.

Participant 3: Right. My company, they offer insurance, it's just way too expensive. If they were to take that out of my paycheck, I couldn't afford to live or support my girls, so I have to suffer. They all have insurance, except for me.

-San Antonio

Not many jobs offer healthcare anymore. My job has a sign that says, "If you're not here on time, don't bother showing up." That's even if you're sick. - Laredo

Yeah, I really have to be barely able to make it out of the house or something, then I'll go to see a doctor about it. - Tyler

Several men said that lack of time due to their children's' schedules made it difficult for them to exercise as much as they would like.

I get home at 5:00, and then if you're going to do exercise you're not going to stay with your kids, and then they go to sleep at 8:00 or 9:00, so you only have three to four hours, and then, if you're doing exercise in that time, there's actually no time to do exercise.

-Tyler

When asked who they talk to about their health concerns, many fathers in the groups said that they talk to their partners. A few men discussed health concerns with their own parents, with men in Laredo saying that they talk to their mothers, but would not talk to their fathers or male friends because they would make fun of them. A few said they talk to their doctor, but typically only when there is a serious, specific health issue to discuss. Participants overall were not likely to talk to healthcare professionals about their concerns. A few men said that they do not discuss their health with anybody and try to get through their issues on their own.

I really don't talk about. The only person who knows, like my mom or something, that's it. There's nobody that's just like, "Oh, let me see what I can do to fix it," or "Let me see how I can help you to fix that." I'm a trooper. I'm the type to ride it out, yeah.

- San Antonio

## **Accessing Healthcare and Annual Physicals**

Few participants had been to see a healthcare professional in the past year. Those who had went for the following reasons:

- ♦ Chronic migraines
- ♦ Flu shot (mandated by work)
- Physical (mandated by work)
- ♦ High cholesterol

Several of the fathers said they used to get annual physicals when they were younger and playing sports because they were required. Many participants said they have not had a physical in several years, saying they do not go to the doctor if they do not feel sick, that they do not want to get bad news from the doctor, and that they do not want to spend the time and money required. A few men pointed out that, even though they do not get regular checkups, they do encourage that health behavior for their children.

When I don't feel bad, there's no point in going. Like if nothing hurts, I think I'm doing good. - San Antonio

Mine was covered [by insurance] and I still didn't go. I know I should've... I haven't had one in so long. A little bit laziness and then a little bit like don't want to hear anything bad. - Tyler

For me, I work so hard and so much that, when I'm not at work, I'm still working on putting something together and trying to get ahead financially, things like that. I know my health is the utmost important [sic], but it feels like that's just money that could be going in the bank account. - Tyler

It's kind of ironic, too, because I push for the kids to have to get their annual checkups, getting their series of shots. They're going to get everything, and I always make sure, you know — we schedule those. We make sure, "You've got to go to the doctor. You've got to go to the doctor." - San Antonio

A few participants had had a physical in the past year, some because they were required to do so for their job, one because he could get a better rate on his health insurance and it was free. A few fathers who had had a physical exam recently described frustrating experiences with long waits to schedule an appointment and long waits at the office even with an appointment. Men who rely on the emergency room as their primary provider spoke of being charged a lot of money for basic care, which soured their feelings about getting healthcare at all.

I called thinking, "I'll get an appointment next week," and they went, "We don't have anything for two months." I said, "Okay, can I have an appointment?" They called me a week before. They don't tell me really anything, they just remind me that I have a doctor's appointment. When I get there, I wait for two hours after my appointment is scheduled, and when I go in, the doctor comes in and says, "How are you doing?" He asks me for a little of information and then he starts flipping pages, "So, you don't have any blood work done." I said, "Well, nobody told me to get blood work." He says, "Well, I can't do anything if you don't have blood work." - San Antonio

I think it's funny. When I do the yearly physical and I set an appointment, I still wait for like 45 minutes. I set an appointment at 3:00, and I get there and I'm filling out papers. I even get there early and I fill out a paper, and then I'm just sitting there waiting. I'm like, "Didn't we have an appointment?" That's one thing that's frustrating.

- San Antonio

Participants said they would expect doctors to check their blood work, blood pressure, height, and weight at an annual physical. Some participants in San Antonio wondered if a prostate or testicular exam was part of an annual physical, and, if so, that would make them less likely to schedule an appointment. However, these participants said that time and cost are more significant barriers.

# Participation in Prenatal Care

Many of the fathers in the groups had gone to at least one prenatal medical visit for their youngest child, with most men having attended a sonogram appointment. Some men in Laredo said they went to a majority of the prenatal appointments. Some men shared that, even though they wanted to come to the appointments, they were constrained by their work schedules.

With my oldest daughter, I went to everything, all of the checkups, everything afterward, but with my one-and-a-half-year-old, I really didn't go too much. I didn't really have time to. I was constantly busy, and with my type of job, I really can't take off. There's a

set schedule. The only time I took off was for the sonogram and then, of course, my baby being born. Other than that, I'm already missing enough work as it is, so I can't miss more to go for her checkup. - San Antonio

My job...I told them I wanted to be a very good support for her being there. When I went to the appointments I always seen, sometimes, the couples and then I'd see the people that were alone. It's just like, I don't want my wife looking alone, and feel like she's — because they go through the emotional stage when they're pregnant, so I don't want her to hold something against me...I waited for her to tell me, "It's okay, stay at work," because I would literally leave work even when work didn't approve it, and I'd say, "I'll just take it," because I don't want my wife just to — I want to make sure that she knows I support her 100% and she's not alone. - Tyler

When asked how involved they felt during the prenatal appointments, many men said "not very" or "not at all," though several participants in San Antonio said they did feel included and welcomed by the healthcare providers. Most men remarked that there were not materials or messages for fathers at the doctors' offices, that what they received was either inclusive to both parents or targeted just to moms. Several fathers explained that doctors and nurses would often talk just to the mother, and that they were ignored during the appointments. One man in Laredo, however, said that he was fitted with a belt at an appointment that simulated contractions so he could feel what his partner was going to experience during birth.

Participant 1: I was going to say something about that because you were talking about access to this information for men and everything. Just thinking about it, when you go to either when she's having the baby or at these prenatal things, there's a ton of nurses around. There's all women talking to your wife. They don't have much to say to you, but there never really are any men around telling you what to expect or how it's going to be. You just sit there and wait for all the women to say it's okay.

Participant 2: Men are left out.

Participant 1: I would've appreciated it if there were a competent, like a non-female nurse every now and then who was competent and could talk about what to expect.

-Tyler

Participant 1: Just the fact that they would just call me Dad. Like, "Hey, Dad, come on in." That makes you feel comfortable. It makes you feel wanted, I guess.

Participant 2: They're very informative because they know a lot of people don't go...The ones that do go, they want to make it comfortable.

Participant 3: Exactly. Some of the doctors, "Oh, it's nice to see Dad came along today." Like, yeah, that's my baby. Am I not going to be here?

-San Antonio

## **Participation in Postpartum Care**

Very few participants in San Antonio or Tyler had attended a postpartum appointments with their partners. Several of the fathers in Laredo went to a postpartum appointment, though they said they sat in the waiting room and were not invited into the exam room. Some participants were unaware of postpartum appointments generally, and/or were unsure if their partner went for those after their most recent pregnancy.

## **Breastfeeding**

When it came to breastfeeding, several participants said the nurses at the hospital helped them get started in supporting their partners and babies. Some men said that the WIC program and its lactation consultants helped them learn the mechanics of successful breastfeeding. A few men said that when they encountered problems with breastfeeding (e.g., poor latch, low supply, fatigued mother, needing to feed the baby while the baby's mother was away), they switched the baby to formula. One father in Tyler described receiving hands-on breastfeeding training at the hospital and that he was grateful for that detailed instruction, though it was because his daughter was in the NICU.

We went through that, but we learned all that from the WIC office, that lactation consultant and all that...But the doctors and nurses at [the hospital], they didn't really. They did, but not much of how to hold the baby, how to do it, this position, that position, and giving dad the information that he needs to have as well. I didn't get that from the hospital, I got it from the WIC office here in Tyler. - Tyler

Actually, my daughter, she is special. She was born prematurely. It was a high-risk pregnancy, so we had to schedule a doctor twice per week. It was very hard. One thing, actually, I liked a lot, when my daughter was born she couldn't breastfeed. The nurses always took the time to actually teach me how to do it because I knew, my wife, she had to pump it, and then to breastfeed – if you're going to a three-hour cycle of sleeping, feeding the baby, that would only give my wife one hour because she had to pump as well. You

cannot do both at the same time. It was actually — I liked it a lot that they always taught me how to do it, everything. I don't know if they do it to everyone, but I know they did it to me, so I feel like there was a lot of information that was missing, and they actually helped me with that. - Tyler

### Safe Sleep

Overall, most participants had heard messages about safe sleep for infants including do not co-sleep, keep blankets out of the crib to prevent suffocation, put babies to sleep on their backs, and do not let babies go to sleep with bottles in their mouths. Participants said they heard these safe sleep messages from their children's mothers and materials they received in the discharge packet from the hospital. While the men said they practice most of these recommendations, they also said sometimes the baby co-sleeps with the mother.

## **Family Planning**

Participants' responses varied when asked if they and their partners had planned pregnancies. Some men had used birth control before attempting to have a baby, and then stopped using it when they decided to get pregnant; many men had not done any planning around the pregnancies. Participants in Laredo said they did not plan the pregnancies in any way, and that that behavior is common in their community. Several of the fathers brought up wanting to have their children close together so that they can grow up together and so that the children would be grown up and out of the house before they as fathers get much older. Several men said that they had discussed birth control methods with their partner, but that ultimately, those decisions were left up to her. When asked what their role was in deciding whether or not to have more children, many participants were quick to point out that more children requires more money, and that weighing the financial implications of future children was part of their role as fathers.

My wife has a device in her, and we're going to wait a year and then maybe discuss it, but then I'm going to get snipped. - Tyler

You could do a study of all Laredo about who did any family planning, and it would be no one. - Laredo

We didn't worry about the costs until the third [child], and then I said, "Okay, we'd have to add a room onto this house we bought and stuff, so the spree was over, but we're talking about the fourth one. It is being planned this time. - Tyler

## **Birth Control Knowledge**

Overall, men in the focus groups were not well educated about the wide range or functions of available birth control methods. Most participants said that they learned about birth control methods from their partners, while only a few said they talked to anyone else about the topic. A few men said they talked to a healthcare provider about birth control, which was brought up at a postpartum appointment.

Similar to the experiences of women in the preconception focus group, some of the fathers in these groups remarked that they found doctors to be "pushy" when it came to recommending birth control. A few participants seemed to dislike that doctors asked about using birth control methods at postpartum appointments at all.

I find doctors are very pushy on [birth control.] I'm saying because...we both, my wife and I come from big families. She's eight out of eight, I'm seven out of nine, so we love kids. I know we're getting older, coming closer to the deadline, but I was shocked when the doctor recommended birth control to her. That was the first thing he said after we had our child: "Have you thought about birth control?" - Tyler

I don't know if we felt uncomfortable, but my wife brought up that immediately after having both babies. We had two different doctors, and both times they immediately started talking about, "What kind of birth control are you going to do now?" She's like, "Well, I'm not." She felt like – I don't know...She was a little irritated. - Tyler

# **Pregnancy Spacing**

When asked their opinions on a good period of time to wait between pregnancies, most of the fathers said between a year and a half and two years to allow a woman to become prepared physically and mentally for another pregnancy. Most participants had not heard any recommendation from any healthcare professional about pregnancy spacing. A few men remarked that, "You are never ready," or otherwise expressed that children come whenever they come and parents have to figure it out as they go. Several men in Tyler explained that, while they did not want to have another baby yet, they were having sex with their partner without using any birth control methods, other than withdrawal.

Participant 1: It's almost like – it's like I don't know if I should pull out. It would be weird to me now. I'm just being honest with you because – I would probably – I think birth control, if she doesn't want a baby right off, it would probably be in the best interest for her.

Participant 2: There's something amongst us men that's called the "pull-and-pray."

-Tyler

#### **Sources of Health Information**

The fathers in the focus groups said that they get information about staying healthy via TV commercials or online, either through Google or Facebook. Some said they follow social media accounts such as Men's Health Magazine for fitness information. Some men talk to friends and peers at work or in their church about the experiences they have had to learn about health conditions. Several participants said they will Google their symptoms and look at WebMD if they are feeling unwell. Several of the fathers shared that they wished they had a professional source of medical information, such as a primary care doctor, but that their lack of insurance has prevented them from having affordable access to such a source.

Participant 1: I wish there was a doctor or someone I could call and say, "Hey, I have this pain. What should I do? Is it serious or should I go to the hospital?"

Participant 2: Without having insurance, you don't have a primary.

-San Antonio

Many of the fathers said that their children's mothers are active in "mommy groups" on Facebook. These participants reported that the women get valuable recommendations from other mothers in the groups which have helped them find doctors and lactation consultants. Participants also discussed how their children's mothers would often share with them what they learned in the groups, making it an important source of health and parenting information for them both.

Participant 1: My wife's in a Facebook moms group or something...she made sure to bypass [the lactation consultant] at the hospital because in her mom's group everyone said, "The WIC's are more passionate, and it's either free or much less expensive." She bypassed that, so she's got most of the knowledge, but she's in a couple of Facebook groups I know.

Participant 2: That's how we found the best doctor for the tongue tie – my wife did – through that moms group on Facebook. Most of them recommended the same doctor in Fort Worth and went with it.

Participant 3: My wife had a natural birth after a cesarean with the second child.

Apparently, most doctors don't want to do that. Through her Facebook group, everyone told her who was the best doctor in town to do that. -Tyler

None of the men in the groups were in similar social media groups aimed at fathers, and most did not have other males in their lives to talk to about their health. Participants were asked how male roles models in their lives, such as fathers and uncles, approached their health. Some participants said those men were largely absent from their lives growing up, so they did not set an example. The norm among participants was that the adult men who were present in their lives did not talk about health. Only a few said that their fathers helped instill healthy behaviors in them growing up like growing fresh vegetables or having fruit trees.

Everywhere we did move, he would have a little garden. He would try and plant watermelons. Tomatoes were a big thing because they're easy to grow. I kind of passed that along to my son and my daughter. We don't have a huge yard, but I have several pecan trees, a peach tree, nectarines, lemons, limes. I just recently planted — I dug out a space for a garden to try and do some more vegetables. He passed that along to me, so that's a good thing. - San Antonio

#### Online and Traditional Media Use

Many participants said that they use Facebook, Twitter, and Instagram. A few said they use LinkedIn and Snapchat. The fathers in the groups said they use Facebook to keep in touch with family and keep up with sports teams and news; some brought up buying and selling items on Facebook Marketplace. A few men said they use social media only for promoting their businesses. Men in Laredo said they use Facebook for political and immigration news.

Several participants said they listen to local radio stations, though usually just when they are in the car. Some men listen to online music streaming services such as Spotify, Pandora, Amazon Music, and YouTube. Those that do reported that they typically listen to the free versions of those services, which include ads.

Aside from watching sports, most men said they do not watch cable or satellite TV, but instead use streaming services such as Netflix, Hulu, YouTube, and Amazon Prime.

Some men said they do have cable in their homes, and typically watch the news or Sports Center.

Some participants reported that they use health-related apps including NikePlus and MyFitnessPal. A few had either Fitbits or smartwatches that they use to monitor their health.

## **Materials Testing**

Participants were shown health education information in printed materials, websites, and an app in order to gauge their reactions and learn more about topics and formats that are of interest to fathers of young children. More information on these resources is available in the Materials Descriptions section.

### **Power Your Family Pamphlet**

Participants generally liked this pamphlet, explaining that, for some, they had never before considered the questions it raised around birth spacing. Overall, the concept of birth spacing, or a recommendation for an ideal amount of time between pregnancies, was a new concept for the fathers in the groups. Some men became defensive after

reading the pamphlet since they already had children closer together than the recommended 18–24 months. Yet overall, participants agreed that the information is good to have. Many men remarked that the question of whether they could financially afford to have another child caught their attention, saying that it is an important consideration. Some men thought that the pamphlet was created for women, but most participants liked the information in it and found it helpful.



You don't really think sometimes when — do I want her protected, but you don't think about how that would affect — does your wife, is she ready? Is she physically and mentally healthy enough to have another baby? I never really considered it...It's very helpful. I

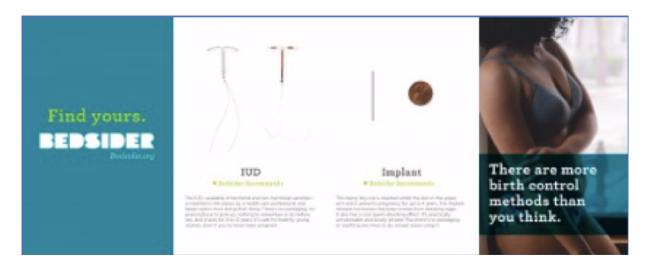
wouldn't say it's necessarily needed to be intended for couples because it makes you think, like you just said, about your wife. Make us consider them.

#### - San Antonio

It's informative, but it kind of puts it in a negative light to have kids close. Like you said, we want our kids to go to school together, grow up together. My brother and I are a year and a half apart. My wife and her sister are a year and a half apart, so we wanted them to be close in age. We knew that we wanted four, so we were like, "We're just going to go to four and then stop." If we would have read something like this, I don't know. It probably would have changed our mind. – San Antonio

### **Bedsider Birth Control Pamphlets**

Fathers in the groups generally reported that they learned something new from these materials. Many men said they were not aware of the several types of birth control shown in the pamphlets, including the female condom, ring, spermicide, and sponge. Overall, participants liked that the information was presented in a straightforward manner, and that it included visuals of the different methods. Some men said they feel like these are made for high school sex education classes, though they also added that they were not taught about these methods when they were in high school and wish that they had been.



Yeah, honestly my wife's so interested [in birth control methods] that I take a backseat and I just let her do everything. Maybe shame on me, but if I actually thumbed through this, I'd be a little more versed. - Tyler

It's very accessible. It has a lot of information. It talks about a visual way to explore and compare every available method. It's not giving you an opinion on this is bad, this is good, this is dangerous. - San Antonio

Participants in these fathers groups and their partners are not well educated about how various birth control methods work, and, in some cases, are currently not using birth control because of their unanswered questions about side effects.

Participant 1: The mother of my children, she had an IUD when we met. She didn't know that she could take it out until a couple of years after. We waited two years before we had our first child.

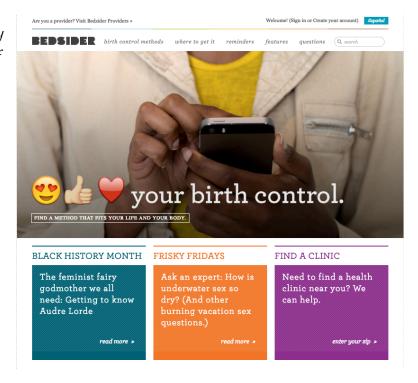
Participant 2: They tell you about it, those IUDs, those implants whatever, but they said there are potential bad side effects. That's what scared my wife from getting it.

-San Antonio

#### Bedsider.com

Participants said that some articles on the site caught their eye, but that it seemed more geared toward women than men, and maybe for people younger than themselves. Throughout the groups, men remarked that they are used to being online and on their phones, so websites and apps would be a good format for them.

Most of the time we use phones...I feel like that's the way to grasp me. I'd rather read it off a phone, to me personally, that type. I read books and everything else because it's still informative, but if I can read off the phone, I can just click on what I want to. - Tyler



### Father's Playbook App

Several participants noted that it is nice to see a product that is specifically for fathers. Men said they liked the financial advice and how to get ready for baby in this resource. Some pointed out the information about dads taking care of themselves as a positive aspect of the app. Some men said the design was simple and easy to use. Several men said that their partners had similar apps such as BabyCenter that they used throughout their pregnancies, and that having an app like this one for dads would have helped them feel more connected to what was happening.

I would've liked the synthesis of relevant information, and it would've made me feel more a part of it. My wife, yeah, she's hearing that and she's reading literature and talking to nurses and all that, but if it was all the pertinent stuff that was going on and I could stay plugged into that, yeah, I think I would've talked to her more about what was going on.

- Tyler

It seems like it's basically preparing you to be a dad. It's got little tabs on here, "Preparing for Baby, Staying Healthy, Pregnancy Basics," so it tells you what to look for in mom. How to help mom do everything. It even has a financial, I guess, monthly savings goal — a financial calculator. I think that's cool. It would be helpful for me. -San Antonio

Some of the fathers said they would want an app to send them notifications to help them get excited during the pregnancy. Another suggested feature was to have timely information about what to expect at certain developmental milestones for their babies, such as teething. Some participants said they would appreciate getting reminders from an app on ways to support their partners in caring for a new baby. Participants also said they would want to be able to search by keyword (such as "swaddle") to find relevant information quickly through the app.

Participant 1: For me, that's the swaddling and, like I said, the growth spurts and the teething. It just seems like all of a sudden, your baby's been happy, and now it's like shrieking in pain and you're going, "What did we do wrong?"

Participant 2: That could be part of the postpartum checklist. It gives you a ding like,
"You're in one month, you should start preparing for or start expecting..."
-Tyler

Participant 1: Or watch the baby today, let [your partner] get out for a little while... I'm learning that it can cause problems if you don't give her that break. Mental health, just keep her happy.

Participant 2: That's why dads need to be more involved in all of this. We just need more information.

-Tyler

## **Key Topics and Communications Channels**

Participants were asked for their final thoughts on information they'd like to have and how to reach them with health information and messages. The fathers in the groups said some topics they would like to see discussed more often include changes in relationship dynamics after baby arrives, feeling connected to the baby, financial considerations (including cost of diapers, formula), checklists of what to buy before baby arrives, how to manage disagreements with their partners around caring for the child, and vasectomies.

...the way that the relationship dynamic changes. When my wife had our second baby, I was kind of used to it kind of being us — you know, like us and my son, and then it completely changed, and all of the attention shifted to the kids. It was hard. I'm not trying to say I wanted all of the attention, but it was weird to see that dynamic shift. Nobody really talks about it. - San Antonio

When asked where they spend time outside of work and home, most men said that work and families keep them busy and they have little free time. Some did say they play intramural sports (softball, soccer, basketball), belong to a church community, take their kids to the park, go to the movies, and sometimes watch sports games at bars or friends' houses. Some men said they go camping, hunting, or fishing. Some San Antonio men said they go to the local theme parks like SeaWorld or Six Flags or to the monster truck rally.

When asked where men like themselves could receive health information similar to what was tested in the focus groups, participants suggested at daycares, in young adult classes at church, and in hospital discharge packets as well as advertising items like the Father's Playbook or birth control information on Facebook and other social media. Men also said the Father's Playbook app should be advertised in moms' groups on Facebook because their partners often share what they see and learn in those groups. Some of the fathers said they would like the ability to chat online with other dads about

questions they have, stating that knowing that they are not alone in their parenting issues would be reassuring.

Participant 1: Put it in a Facebook mom groups.

Participant 2: "Hey, you need to download this app right now."

-Tyler

#### Conclusion

The top of mind health concerns for fathers in these focus groups are diet, exercise, stress, and lack of sleep. When asked what prevents them from addressing their health concerns, several men brought up not being able to afford primary care. Many participants in the groups did not have health insurance; even those who did struggled with high copays and costs. In Laredo, none had health insurance and several had jobs that do not offer insurance.

Many of the men said they have not had a physical in several years, saying they do not go to the doctor if they do not feel sick to avoid the risk of bad news as well as the time and costs involved. A few participants had had a physical in the past year, some because they were required to do so for their jobs and one because of an insurance incentive.

The fathers in these groups had some involvement in their partner's prenatal care, but also faced barriers. Many had gone to at least one prenatal doctor's appointment for their youngest child, typically for a sonogram. Some were not able to attend due to works schedules, even if they wanted to. Across the board, several participants did not feel fully welcome and involved by providers during prenatal appointments, though a few felt very included.

Involvement in postpartum visits was mixed. Few men in San Antonio and Tyler had attended those appointments with their partners and, while several men in Laredo had attended, they often stayed in the waiting room and were not invited into the exam room. Some participants were unaware of postpartum appointments or if their partners had gone to one at all.

Overall, participants were not well educated about the wide range or functions of available birth control methods and a number did not use birth control or do any type of family planning. Most of the fathers said they learned about birth control methods from their partners, while only a few said they talked to anyone else about that topic. In some cases, participants are currently not using birth control because of lingering questions about side effects.

Men said they get information about staying healthy via commercials or online, either through Google or Facebook, and almost never from peers or male role models. Many participants reported that their children's mothers are active in "mommy groups" on Facebook. These participants said the women get valuable recommendations from other peers in the groups (e.g., referrals or tips to find doctors and lactation consultants). Participants also said that their children's mothers often share with them what they

learned in the groups, making it an important source of health and parenting information for them both.

The men in the groups generally liked the *Power Your Family* pamphlet. Some explained that they had never before considered the questions it raised around birth spacing. Overall, the ideal birth spacing recommendation was a new concept for participants.

Participants especially liked the *Father's Playbook* app, noting that it is nice to see a product that is specifically aimed at fathers. Several of the men said that their partners had similar apps such as BabyCenter that they used throughout their pregnancies, and that having an app like this one for dads would have helped them to feel more connected to what was happening.

# **Labor and Delivery Nurses**

### **Participants**

SUMA conducted three focus groups with a total of 21 nurses who have worked with women with high-risk pregnancies. About two-thirds of the participants work in labor and delivery; the other third in mother-baby (after delivery). A few also work or have worked in antepartum, where women with identified high-risk pregnancies are hospitalized for days, weeks, or in some cases, months. All worked with at least some low income patients. For a breakdown of the number of participants and the number of hospitals they represented, see Table 6 below.

Table 6: Participants (N = 21)

Location	Participants	Hospitals Represented
San Antonio	6	4
Dallas	7	5
Tyler	8	3

## **Lines of Inquiry**

The interview guide for the three focus groups with nurses is included in the Appendix. The lines of inquiry included:

- Experiences as nurses working with women who have a high-risk pregnancy
- Perceptions of what constitutes a high-risk pregnancy
- Hospital protocols and practices related to high-risk pregnancies
- ♦ Level of knowledge and training in managing high-risk pregnancies
- ◆ Barriers to comprehensive healthcare for women with high-risk status, including transitioning from the hospital to care in the community
- Perceptions of patients' knowledge about pregnancy risk factors, understanding of conditions that could affect future pregnancies, and ability to communicate their health histories and advocate for themselves
- Perceptions about the responsibility for patient education
- Feedback on existing educational materials and brainstorming formats or approaches that would be helpful to women with pregnancy risk factors

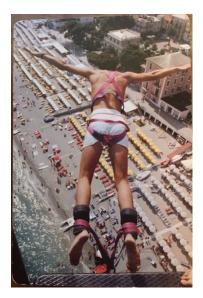
### **Detailed Findings**

As described in the Methodology section, there was an icebreaker discussion at the start of each focus group where the moderator asked participants to select the one image that best illustrated their feelings about working with patients who have a high-risk pregnancy.

One theme that emerged from multiple participants in each group was the unpredictability of the role, and the need to be on high alert.

> Ice climbing, so this feels that things can be going okay, then at any moment, just in a second, disaster can happen. - San Antonio

I have a guy and he's bungee jumping. I feel like this sometimes because I'm a new nurse. You kind of never know, even in the regular situation, what you're going to get out of a day. When I get high-risk patients, I'm always on high alert because this person needs this attention or that attention. -**Dallas** 



Several participants highlighted the importance of attention to detail when working with women with high-risk pregnancies.

I chose this because it looks like he's doing something tedious. He has something fine in his hands that he's working with. I also enjoy doing some of the high-risk stuff, but I think it requires an attention to detail. You have to be very focused about what is changing in your patient. You're with them for 12 hours. You have to be very detailed in your assessment. You have to be watching for fine changes as your patient deteriorates so that you can catch it quickly. - Tyler

The importance of teamwork was also highlighted in all the groups.

I have a picture of what looks to be like a mass transit sort of highway, where it's going all different directions. This reminds me, because at our hospital we've got multidisciplined people helping us take care of these patients, thankfully, and we've got people going here and there and everywhere, but together as a team usually we have pretty good outcomes, which is a good thing. - San Antonio

...the cowboy is the leader. As a nurse, you have a big role in the care of that patient, especially the horse being different, collaborating with pharmacy, collaborating with specialty. It just takes so much more teamwork to come in on that one patient. -Tyler

## Signs of a High-Risk Pregnancy

Participants in all three groups identified obesity, diabetes, and high blood pressure as the most common conditions that make women high-risk maternity patients. While not as prevalent, hemorrhaging, clotting, placenta issues, and preeclampsia concern the nurses the most. They also mentioned a number of other conditions that make them consider a patient high risk:

- No prenatal care
- Substance abuse
- Sexually transmitted diseases (STDs)
- Preterm labor or ruptured membranes
- Serious health issue like cancer, stroke, or transplants
- ♦ Small stature
- Anxiety and other mental health issues
- Advanced maternal age (age 35 or older)
- Multiple gestation (twins, triplets)
- Congenital anomalies

# Protocols for Caring for Women with a High-Risk Pregnancy

The moderator then asked the participants to describe their role as nurses. This included a discussion on if their hospitals had protocols specific to caring for women with high-risk pregnancies as well as if they had any special personal practices or protocols for caring for these women.

Across the board, participants came across as knowledgeable about how to care for women with high-risk pregnancies. Several said the nursing skills related to caring for women with high-risk pregnancies come through both training and experience. In every focus group, several participants said they receive ongoing training at their hospitals related to dealing with high-risk pregnancies. They mentioned specific training in advanced fetal monitoring and hands-on simulations for pregnancy complications such as hemorrhages. Several said they have to meet annual continuing education competencies.

These nurses have learned what to expect and how to respond. They know how to assess and monitor their patients, and what changes to report to the doctor. They know when extra lab work and more frequent blood pressure checks are called for, and how to watch for the side effects of medications. They understand the importance of preventing clots by getting women who are obese up and walking, deep breathing, and coughing. In two of the focus groups, participants described the nurse's role as the eyes and ears of the doctors.

We are right there. We are the ones that see the stuff first before the doctors, because the doctors are still doing office hours, while we're the ones that are taking care of the patients. – San Antonio

...if it's a pregnancy-induced hypertension, then there'll be certain things that we would expect to do with those moms. We're going to expect to do a 24-hour urine. We're going to expect to do liver enzymes...there's lab work and baseline things that we expect to do that's not necessarily a written protocol, because the doctor is still going to have to write those orders, but we would expect that, and if we don't get that we would ask for it.

- Dallas

All the participants said their hospitals have protocols in place for caring for women with high-risk pregnancies. They gave examples of some specific protocols that guide their decisions and actions.

Let's just say with hypertension. We have protocols and procedures on how often we monitor their vital signs, but that can vary depending on if it is elevated. Then we have other interventions that we have to do to hopefully bring that blood pressure down to a safe level where they're not in the stroke range. – Tyler

Another protocol we would have is if there was an abnormal placenta placement. If the placenta is low lying or if it's a complete previa... if the placenta is going into the uterus, then we would have IVs, and we would sometimes even get a PICC [a type of catheter] line put in ahead of time...do lab work every three days. – Dallas

The great majority of participants believe that hospital staff and doctors do a good job of following established protocols. Some participants gave examples of how their hospitals are working to strengthen protocols for high-risk pregnancies. For example, one noted how her hospital in San Antonio participates in the AIM project and, as part of that, is working to standardize the expectation of care for postpartum hemorrhages. Another who works in San Marcos described how, after the nursing staff pointed out problems, the hospital increased core nurse staffing and started: requiring the presence of a neonatologist at every cesarean delivery (C-section); created an in-house obstetrician (OB) position; instituted new protocols; and required active training with a

mock hemorrhage. Participants in Tyler described one hospital's focus on evidencebased practices and process improvement.

There's several different committees that each meet once a month bringing in new things — they're evidence-based practice — and also just reevaluating things that we already have implemented. -Tyler

In terms of a hospital's capacity to provide comprehensive care to women that are high risk, there was a distinct contrast between communities that have access to a maternal-fetal medicine specialist and those that do not.

We have a maternal-fetal medicine director. His whole job is to take care all of these high-risk people, wherever they are, wherever they come from, up in the units, wherever. He comes and every day he does rounds on all of these patients. He's got hands on in their care, making sure that all of the disciplines that need to be working with these patients are communicating to each other, because sometimes there's multiple doctors. I think that's been great. - San Antonio

I know we're trying to get high-risk physicians, maternal-fetal medicine. Right now, they're in Longview, they're in Dallas, and they have to make phone calls in order to get recommendations, but our hospital's actually working on getting them at least a teledoctor there, even Skype with the patient, just get more access to provide care because we have a lot of high-risk patients. We have a lot of hypertensive, lot of diabetes. People are not as healthy as they should be to be pregnant, so I think bringing that in will help the city. - Tyler

Very few participants mentioned any other hospital staff dedicated to helping pregnant patients address their risks. One Tyler nurse said the addition of an OB hospitalist available 24 hours a day has made a difference for high-risk patients. Another bemoaned the fact that her hospital once had dietitians and diabetes educators, but no longer employs them. One participant said her hospital at one time included a visit from a home health nurse in the discharge orders for high-risk patients, but no longer offers this service. A San Antonio nurse mentioned a patient navigator system at her hospital.

I think it is very helpful for some of our high-risk patients. Maybe their normal OB appointments can't get to some stuff, so they actually will come see a L and D [labor and delivery] nurse, and that L and D nurse might organize the multi-disciplinary meeting, where they are going to meet the newborn intensive care unit team who's going to take care of their baby that's high risk, or you're going to look at all of these things.

- San Antonio

The sheer numbers and percentage of high-risk women and babies represent a significant challenge to providing comprehensive care. Some of the Tyler nurses said that 80% of the patients they see each day have high-risk pregnancies. Nurses from one hospital in San Antonio estimated 50% or more of their patients are high risk; others in that focus group said 75%. Nurses in Dallas said they care for three to four couplets (mothers and babies) during a 12-hour shift at their hospital, regardless of acuity, and the workload can become daunting.

There's a well mother baby, and you're doing vital signs and doing all the normal stuff, but then they throw in a baby that's on blood sugar checks every three hours, and a mom that's on blood sugar checks every three hours. And then antibiotics over here, and then your baby goes on phototherapy, and then this baby transfers to special care because they're not ready to go home. Or this baby doesn't eat well. – Dallas

### **Continuity of Care**

The moderator asked participants if they perceive any gaps in continuity of care for patients transitioning from the community to the hospital and back to the community. Some participants noted that continuity of care depends in part on how well prepared the women were before they came to the hospital, what services and resources they can access, and what awaits them at home.

Are they going home to a houseful of kids where nobody's going to help them? They can't really pay attention to themselves, like check their blood sugars, check their blood pressure. – San Antonio

Nurses who work with low-income patients cited a lack of knowledge and preparation on the part of many of these women before they arrive at the hospital. They see patients who have not had prenatal care, not taken childbirth education or parenting classes, and are not prepared to care for an infant.

I have patients that are delivering the next day and they don't even know who their pediatrician is going to be. – San Antonio

We can't find their prenatal records...whether they've had their vaccinations, whether the baby has been okay, is the baby growing in the right size. There's no ultrasounds or sonograms. None of that is there. There's a gap in the care because they haven't had that prenatal care, and then they come here and they just deliver. - Dallas

Participants in Tyler pointed out a gap in the continuity of care after women leave the hospital, which they attributed to limited Medicaid coverage.

Tyler Participant 1: We get a lot of patients that are always gestational diabetic, but they suffer with these symptoms all the time and they're probably really a type 2 diabetic. Some of these women are only getting healthcare in pregnancy, when they need to follow up.

Tyler Participant 2: It has to do with insurance. A lot of them only have insurance when they're pregnant. They have pregnancy Medicaid, and other than that they have no access to care because they do not have insurance.

Even for women who have insurance coverage, participants discussed how a number of things may interfere with care after they leave the hospital. The discharge nurses may help a patient set a follow-up appointment, or advise her to call her doctor and schedule one. Yet, once she leaves the hospital, the nurses have no way of knowing if she followed through. They see women struggling with barriers, such as language and communication, transportation, the responsibility of caring for other children or of being a single mom, the prospect of juggling work priorities with wait time to see a doctor, lack of child care, and a limited understanding of the importance of a postpartum appointment and continued primary care. According to participants, discharge materials from hospitals and doctors are usually geared for the general population, not high-risk patients, so women who have health issues that need follow-up care may not be fully aware of the dangers. (This finding was echoed in the women with high-risk pregnancies focus groups discussed earlier as well.)

When asked what could improve the transition from the hospital to the community, participants in every group suggested that someone to follow up with the high-risk women after they go home by phone, or ideally, with a home visit. During the home visit, a nurse could check blood pressure, blood sugar, confirm the woman has filled her prescriptions, look for signs of depression, observe the condition of the home, and provide referrals for any necessary social services.

# Perceptions of Patients' Knowledge

In addition to discussing prenatal and follow-up care, the moderator explored the nurses' perceptions of their patients' level of knowledge and understanding of their pregnancy risks. This included discussion on patients' level of understanding of the potential long-range impacts of their conditions.

In every group, participants said many of their patients do not understand the seriousness of their health risks or the potential impacts on current and future pregnancies. One nurse in San Antonio estimated that only 10% of her patients appear

to truly understand the ramifications. Many patients seem to believe the diabetes or high blood pressure that has made their pregnancy high risk will go away after the birth of the baby or will be treated easily.

Especially something like with pre-hypertension or even with gestational diabetes. They think it's something that they have now, and they're going to get over. They take a pill and they're done...They don't seem to understand. Even preeclampsia, if you don't take care of yourself, you can develop chronic hypertension, and they don't seem to get that, either. – San Antonio

They feel like okay, just bring me my insulin. You're fixing my problem. I'm going to eat what I want to eat and you're just going to bring me my insulin and my blood sugar is going to go down, so the problem is fixed. I don't think they think long term, that this is going to be a problem. - Dallas

According to participants, patients may also have difficulty grasping the impact of diabetes and hypertension on their pregnancy and long-term health because these conditions are so common in their family and community, as described by nurses in Tyler.

Participant 1: I think some of it, too, is just their family. It would be out of the norm for them to care about these things when their family in general doesn't care, and so they'd be weird and be looked at differently.

Participant 2: *Everybody's diabetic, everybody has high blood pressure.* 

Participant 1: It's like it's not a big deal to them.

Seeing such high numbers of high-risk pregnancies can desensitize healthcare providers too, as noted by two of the nurses in Tyler.

Participant 1: Yeah, it gets to be the norm too, though. At the same time, you almost get immune to some of it without meaning to. Everybody's diabetic. Everybody has high blood pressure.

Participant 2: Yeah, it feels more abnormal to be normal. When I have a patient that doesn't have anything on the problem list, I'm like, "Are you sure? You have nothing?"

A few nurses in the focus groups noted that the pregnancy experience alone can be overwhelming, detracting from patients' ability to grasp the seriousness of their risks, pay attention to guidance, and advocate for themselves.

Can you imagine, you just had a baby and, even if you took a class, the classes aren't going to talk to them about their medical diagnosis. Now, I have had a child, my body's tired, physically recovering in some way, and now you're going to teach me how to take care of my body, take care of my baby, meet my normal daily needs, and oh, you have this that happened to you and you need to watch out for this. They're bombarded. Where do they have time to soak this in? - San Antonio

# **Responsibility for Educating Patients**

The moderator asked participants who could help patients in more fully understanding their healthcare needs. This included discussion on who has the most responsibility for education. Many of the nurses believe that the patients' providers at OB/GYN offices should play the most important role in educating patients with a high-risk pregnancy about what to expect during delivery.

It would be nice beforehand if, at the offices, specifically places that saw high risk, maybe a lot of the Medicaid offices, if on some of their prenatal visits ... there was a nurse or somebody to say, "This is what you have. Here's what to expect. Here is our game plan for you," and really have some one-on-one time with the patients to help them understand. They're already there to see the doctor, they're coming to their prenatal visits, that's the time to do it. - Tyler

However, participants conceded that women who skip prenatal care would not have access to this educational opportunity. Some expressed doubts that women who do get prenatal care are educated adequately about their risks.

I know our Medicaid clinic, they hardly get any education there because they just have to get patients in and out so fast. They're providing the basics, they don't have time to sit and educate them, especially the way some of them need to be educated and spend way more time than the typical person. – Tyler

The thing is, the physicians don't take that time during their office visits, because they've got 15, 16 [patients] stacked full during the daytime, and they time it to 10, 15 minutes, come in, check heart tones, are you feeling okay, okay, bye, and that's pretty much how it goes. – San Antonio

Participants also acknowledged that women are often overwhelmed by their circumstances and, even if they have access to information, may not be able to understand, remember, or communicate it to others.

I don't think it's necessarily that they're [OB/GYNs] not doing a good job; it's kind of what the patient is retaining. They're in for their ultrasound and they're all excited about the ultrasound, and then, "Oh, she said something about my diabetes. I forgot."...That's even in the hospital when we're sending them home. They only retain probably maybe 30% of what we go over and tell them. - Dallas

I was trying to take care of somebody that we don't have all the pieces to the puzzle. We don't even know, and then we find out this, we find out that, and it's like oh, that changes this. Sometimes they are clueless; sometimes they know and they just haven't said anything. - Dallas

Social norms also come into play, affecting the degree to which patients receive and act on information.

And then the ability of people to follow what you say and not, "So-and-so's grandma had this happen, so they don't believe in taking Labetalol because it killed somebody's baby," when it had nothing to do with it. Breaking through those barriers and explaining this didn't happen because of this. Only because your cousin did cocaine the whole time and her baby's fine doesn't mean your baby will be fine. -Tyler

A number of the participants noted that during and after delivery nurses play the most important role in educating patients.

Once they come in [to the hospital], we usually talk to them and tell them what to expect, how things are going to go, and when they might get their epidural if they want one. When we get to the stage of pushing, we tell them how to push, and state the things we're going to go through. We go over a lot of stuff just gradually throughout the day. We educate every time we walk in the room. – Tyler

Now, during delivery, it's us [nurses], because during delivery we're going to be like, "This is what you're here for. These are the symptoms you have, correct? This is what I want you to report to me." – San Antonio

However, some participants pointed out that nurses and doctors can be so busy that there is little time at the hospital for the kind of education many patients need.

Nobody has the time...As a whole, every hospital system is being told to do more and more, and it's sicker and sicker patients. You don't have the time to educate; you don't have the time to go through your chart. You don't have the time for a lot of things, but it's still expected that you do all that. It's the same thing for physicians. They're expected to see more and more and more patients. - Tyler

While the key role they play in patient education cannot be overstated, hospital nurses emphasized that they cannot be expected to be the primary health educators for women with high-risk pregnancies. Most have limited contact with a given patient. Labor and delivery nurses reported that they may care for a patient over a single 12-hour shift and never see her again. Antepartum and mother-baby nurses, in contrast, reported that they may have more extensive contact with patients who are hospitalized longer for serious health issues and may take advantage of those opportunities for education.

When you have the uncontrolled diabetics come in, you can take care of them on a daily basis, you can do their blood sugar, you can give them their insulin, you can take things off their meal trays that don't need to be there. But if you sit and teach them, and teach them how to do that, and how to monitor their blood sugar, what proper things they need to eat, what things they don't need to eat, then you can affect more than just that week or two weeks or the pregnancy. You might change things for their lifestyle. -Tyler

One mother-baby nurse recognized the limitations of education during a hospital stay and stressed the importance of additional education in the community after discharge.

How can we continue that education that we did during the three crazy days that they were in the hospital into the community setting a little bit more...? The high-risk ones, especially because some of them, we may band-aid their issue for those three days, and it doesn't mean a week from then they're not just readmitted right away because they've had another crisis. - Dallas

#### **Educational Resources**

The moderator asked participants what kind of educational resources they have in their hospitals to help women understand their own risks and know what to do for the health and safety of their babies. Resources varied across the hospitals, with print materials being the most commonly mentioned type of resource. Examples of formats included:

- ◆ Educational videos on a variety of topics, in some cases required viewing before the patient can change the TV channel
- Materials nurses can access by computer and print out
- A binder of information that is given to women at discharge
- Handouts that include links and information about relevant apps
- Printed information about postpartum depression with a list of resources

However, all of the nurses agreed that the materials they use are generic and geared toward pregnancies that are not high risk. Participants also expressed doubts that print materials are the most effective approach. The volume of information in a folder or binder can be overwhelming and nurses cannot ensure that patients will read it all. Several said that more visual resources would be helpful for their patients

I would love to see more of really good ACOG [American College of Obstetricians and Gynecologists] patient education videos. So many of these people, we hand them lots of discharge teaching on paper and reading, and ... it's supposed to be fourth grade reading level, but they don't read it. To have ...more visual things, because I don't want to just Google and say, "Hey, look at this video on YouTube." But if we had actual, "Hey, you have pregnancy-induced hypertension. Why don't you watch this?" - Dallas

## **Materials Testing**

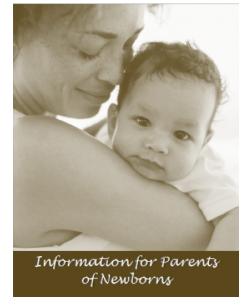
The moderator shared with the participants samples of four existing printed educational materials designed for women who have just had a baby and asked them to review and react to each one. The purpose of this activity was to determine the relevance of the information for their high-risk patients and to identify the formats and features that nurses believed would be most likely to catch the interest of new mothers.

#### **Texas DSHS Information for Parents of Newborns**

Almost all the participants in every focus group had seen this booklet itself or a version

of it produced by their hospital. One hospital provides comparable information through an app. Reactions to the print version were consistent across the three groups. Participants said the book contained too much information, was organized poorly, and presented in a bland, uninteresting format. They offered a number of suggestions for improving it:

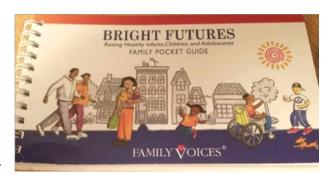
- ◆ Add a bulleted high-level overview of each topic at the beginning of the booklet, and more detailed information later.
- ◆ Organize the information chronologically, starting with topics that are relevant the first 0-24 hours after birth and move forward from there.



- Group information about mother's health topics and baby's health topics separately.
- ♦ Improve the flow put related topics together instead of jumping around.
- ◆ Add information specific to high-risk pregnancies (e.g., signs to watch for postpartum, when to call the doctor, and how to reduce risks next time).
- Add information about getting fathers involved.
- Add information about birth control.
- Put information that will be referenced repeatedly in an easy-to-find location (e.g., put the immunization schedule on the back cover).
- Condense the information to the most relevant details (e.g., cut down the multiple pages on CNV virus, cut down the page on whooping cough).
- Put information on common situations ahead of information about rare conditions.
- Lower the reading level to sixth grade or lower.
- Add more pictures and brighter colors.

### **Bright Futures Pocket Guide**

Participants were asked, "If information about the required topics from the first booklet were put into this type of format, do you think it would be attractive and helpful for new mothers?"



They consistently liked the look of this booklet – the colors, pictures, and spiral binding. They liked the table of contents, colored tabs, color coding, the chronological order of the information, and the list of resources at the back. Participants said the booklet could be improved by increasing the font size and making the booklet bigger overall, possibly doubling its size, and by adding a section specific to women with high-risk conditions.

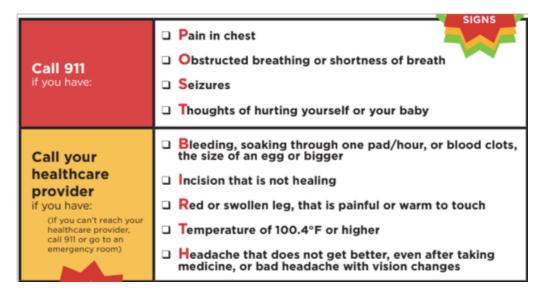
### **Loving Support Keychain**

When reviewing this resource, participants suggested that mothers might be likely to keep such a tool clipped to a diaper bag or that it would become a toy for the baby. However, they questioned whether all mothers have internet access or if they would take the time to type in and look up information. A few said this type of tool might be helpful as a supplement to a booklet formatted like the *Bright Futures* resource.

### **AWHONN flyer**

All the nurses in every focus group praised this flyer, declaring it "fantastic," "great," and "awesome." In particular, participants liked the:

- Attention-getting heading "save your life."
- Red-yellow format informing women which symptoms require emergency attention and which can be addressed with a call to their healthcare providers.
- Bullet point explanations of why certain symptoms require attention.
- Easily understandable language and basic reading level.



Ideas for improving the material included:

- ◆ Laminating it, or printing it on card stock or magnetic material to increase durability and so patients would be more likely to post it on their refrigerators.
- Printing it poster-size for use at clinics.
- ◆ Adding sections specific to high-risk pregnancies, and diabetes, high blood pressure, the most common risk factors.

◆ Creating a parallel one-page resource addressing signs to watch for in the baby – when to contact the doctor, and when to go the emergency room.

Participants suggested that the information would be useful to women at multiple points in a pregnancy. For example, some said the resource should be distributed to women at clinics and OB/GYN's offices, noting that sharing it during prenatal visits when a spouse or other family member is present would be particularly helpful. Participants also said the hospital should provide the resource to women when they arrive for labor and delivery or at discharge.

## **Final Thoughts**

Before adjourning, the moderator asked the participants in each group what had made the biggest impression on them during the discussions and what they thought Texas DSHS could do to best help hospitals address the needs of women with high-risk pregnancies.

Across the board, participants were the most impressed with the AWHONN one-page information sheet. They wanted to take it home with them. They wanted their hospitals to begin using it with patients.

The most common ideas for how DSHS could assist hospitals related to improving continuity of care after the delivery. Several participants suggested that DSHS could offer follow-up home visits from a nurse after women with high-risk pregnancies are discharged from the hospital. Alternatives to home visits might be phone calls from a nurse or case manager, a hotline or referral center for women to call, or an app with a chat feature.

I think if that app had a chat feature, too, some people love a quick resource of chat, "Hey, I looked it up, but I really want to talk to somebody and say, "I'm worried about this or that." Even if that person can't give medical advice, per se, if they can say, "This is the resource that links to this. Here's what I found on that website." It's not necessarily giving out advice, but it's in-the-moment guidance. - Tyler

### Conclusion

The participants in the three focus groups, nurses in antepartum, labor and delivery, and mother-baby units in hospitals, appear to be well trained, competent, compassionate, and dedicated to their work. They have stepped up to become the default real-time educators for women who have not had or have not taken the opportunity to prepare themselves adequately for delivery, including addressing their own health issues. Hospital nurses see firsthand the impact of the lack of prenatal care, lack of well woman care, and gaps in continuity of care that can all contribute to increased risks during pregnancy. They want more for their patients, and would gladly use any additional materials designed specifically for women with high-risk pregnancies.

## **Healthcare Providers**

## **Participants**

SUMA conducted three focus groups during the fall of 2018 with doctors and other healthcare providers. Each group contained between five and 8 providers with a broad variety of specialties including family practice, obstetrics/gynecology (OB/GYN), internal medicine, nurse practitioners, and a hospitalist. While two providers saw as few as 10 patients a day and some saw up to 30 patients a day, on average the providers were treating approximately 20 patients a day. Table 7 offers a summary of the participants by location.

LocationParticipantsDallas6San Antonio5Tyler8

Table 7: Participants (N = 19)

# **Lines of Inquiry**

SUMA researchers used the following lines of inquiry to capture providers' experiences, perceptions, and attitudes about providing reproductive and other healthcare to women. The focus group guide is included in the Appendix.

- ♦ Trends, details, and experiences with providing well woman care
- In-depth discussion of reproductive healthcare provided as well as related perceptions and attitudes
- Experiences in providing preconception, prenatal, and postpartum care
- ◆ Experiences with providing and coordinating care for women with risk factors or high-risk pregnancies
- Available community connections and referral networks for patients
- ♦ Discussion about patient education and education resources provided/available
- Knowledge of public health trends as well as feedback on a variety of health education and patient resource materials as well as websites that offer free resources to providers

## **Detailed Findings**

#### General Health and Well Woman Care

All of the providers in these focus groups offered some amount of well woman care. They all considered well woman exams a very important part of their practices. The range of things they typically cover in well woman exams and care included:

- Birth control
- Blood pressure
- Bone density
- Cholesterol
- Diabetes management
- Heart
- Lungs
- Mammograms

- Medical history
- Mental health
- Nutrition and exercise
- Pap smears
- Pelvic exams
- Sexually transmitted diseases
- Thyroid
- Vaccines, particularly HPV

The specific topics included in each well woman exam vary depending on multiple factors including a woman's health history, age, and reproductive plans.

If they are post-menopausal, then we will be talking about bone health and an EKG.... If they are young, like in their twenties, then the conversation is completely different.

– San Antonio

While some providers reported that they refer certain patients to specialists for exams outside of their expertise, many providers offer screenings and checkups in areas outside their specialty in order to keep the exams done in one place – generally for insurance reasons or because they are in an area lacking specialists.

Mostly, they come in for a regular blood test to check for cholesterol, thyroid, diabetes, and those things. ... Sometimes because of the financial or insurance problem, they say, "I want to get [my Pap smear] done here. I don't want to go anywhere else." I'll go ahead and do it. – San Antonio

A lot of females, they don't go to ... a family practice physician or internist, so a lot of times I end up doing a lot of their routine labs. –Tyler

Providers reported tracking and talking to their patients about important health issues like obesity, nutrition, and diabetes on an ongoing basis. They indicated that, if a patient says they are considering getting pregnant, they try to educate the patient early on the

ways that their risk factors may affect their pregnancy and how they can work towards the best outcomes.

If you're actually getting to do preconception counseling, having them be as healthy as they can before they get pregnant is so wonderful, if possible. – Dallas

Reviewing again their obstetrical history with their complications in their previous pregnancy might've been, and how you're going to look toward in the next pregnancy. – Dallas

### Mental Health

The providers said that the topic of mental health has become a very important part of the well woman exam. In each location, participants brought it up unprompted and commented that a large portion of their patients were being treated for mental health concerns, primarily anxiety or depression. They found that many patients were unaware of their mental health symptoms or conditions and that the well woman exam was often a first line of treatment. Many of the providers find themselves treating mental health symptoms because of limited referral options, especially if the condition requires a psychiatrist as psychiatrists are in short supply.

Women will attribute anxiety, depression, and those kinds of psychiatric conditions to hormones. So, here they are. They're clearly clinically depressed and they want their hormones checked. Access to psychiatric care is a problem. – San Antonio

38% to 40% of my practice is anxiety and depression. - San Antonio

We have a lot of anxiety and depression. It probably relates to a lot of financial instability that they have. Sometimes they are in abusive relationships. That's definitely part of another vital sign, per se. It's on your radar a lot. – Tyler

#### **Patient Awareness**

Participants stated that many women – particularly low-income women – lack education about their health and their own health issues. They expressed the opinion that providers must take that into account when treating these patients. Overall, patients are coming into the well woman exam without a strong awareness of their own health history, risk factors, or other issues related to their health.

I would say, in my health practice, it's the exception to have a patient come in who is well-versed on their history and their medications. Often, they come — what medicine are — they can't tell you. They can't tell you the dosages. They'll tell you things like, "It's a little white pill." It's very frustrating. — San Antonio

They say, "I had an ovary removed." "Which ovary?" "I don't know. They just took an ovary out," and they're not really sure why. - Tyler

The worst thing is when patients have had hysterectomy, and they don't know why. "I don't know. He just said it was time." "Time for what? You had your ovaries removed. Did they take your — do you have your cervix?" "I don't know." — San Antonio

Providers in these groups stated that patients often do not know what should be included in a well woman exam, or how often they should get checked for various issues, which leads to both health problems being missed and unnecessary testing. For example, the current recommendation for women who have no signs of HPV is to get Pap smears every three years, yet many patients still believe that they should get checked every year.

One of the problems I see is that someone is coming in for a well woman exam: "What's a well woman exam?" – Tyler

# Reproductive Health

When discussing reproductive health in the well woman exam, providers described that they have a clear focus on pregnancy plans and birth control. Interestingly, folic acid was not brought up in this discussion, even when prompted by the moderator. In all three focus groups only one provider mentioned or discussed folic acid.

Participants stated that they routinely ask women of childbearing age about their family planning and contraception strategies. In discussions of birth control, the doctors stated that many of their patients are simply not doing family planning.

Half the pregnancies are unplanned in the United States. In our practice, it's more like three-quarters. – San Antonio

The plan is, "I'm here and I'm pregnant." - Dallas

Whenever you ask Hispanic ladies what they're doing for contraception, nine times out of ten you will hear, "He's taking care of me." ... or "I have to talk to my husband about that." – Tyler

The providers mentioned that their patients often have difficulty accessing free or low-cost birth control. They reported that birth control access is further complicated by insurance coverage that changes from year to year with the changing cost for birth control products.

We used to be given tons of samples. If there were individuals [without access] that we identified, I give them 12 months of pills. But those things are gone. – San Antonio

I've noticed a lot of the insurance companies are actually paying a lot more now. ... But what's formulary [readily available] then? They may have to bring us a list.

- San Antonio

## **Prenatal to Postpartum Care**

#### **Prenatal Care**

SUMA researchers asked providers a variety of questions about typical prenatal and postnatal care they provide and the trends they see. Many of the providers in these focus groups reported that they often see women for prenatal care for the first time during the first trimester of pregnancy.

Sixty percent probably do seek care in their first trimester. – Tyler

Most of them come in in their first trimester. - Dallas

For those women who seek care after they are 20 weeks' pregnant, providers cited delays in Medicaid approval as a prominent barrier to earlier prenatal care. With more than 50% of the babies in Texas born on Medicaid, this presents a serious problem.

Their Medicaid's not in. That's a big thing. "We didn't seek care because Medicaid's not in yet. I've waited because I don't have money to pay for my ultrasounds, they're going to charge me for." – Tyler

We've had patients who come. They say, "Doctor, I was six weeks pregnant. I went to Medicaid to apply. I'm 24 weeks. This is why." That's a huge problem. – San Antonio

Participants cited other challenges to timely prenatal cited, including: cultural factors, economic factors, transportation, and just not knowing they were pregnant.

A lot of times it's insurance issues, access issues. They don't have transportation. They just don't know, like they didn't think that they were pregnant or they didn't know where to go. – Dallas

I've seen in my Hispanic population, "My mom said that if I just drank this then I would be okay until it was time to have the baby," or whatever it was. – Dallas

A lot of times we'll have to send the patients from Jacksonville just to meet the OB/GYN's because I like them to know who's going to deliver them, but you act like telling them to go to Tyler would be like saying to go to California. That's a humongous deal for them; money for gas they don't have. They don't have a ride or they have one vehicle between all of the family, and they have no way to get there. – Tyler

Sometimes you get people who've had multiple babies and they haven't had any complications and they don't feel like it's necessary to come in that early. – Tyler

Providers said many women bring their husbands and family members to support them at their prenatal appointments. Participants said they try to encourage fathers to continue attending by engaging them in the conversation as well as in the visit.

I always talk to [the fathers] and engage them in the whole thing." - Tyler

When asked about group prenatal care (e.g., cohort models where pregnant women due around the same time receive routine care as a group), providers did not seem to recognize or respond to that term initially. When further discussed, only one provider reported currently offering group care and a few others were aware of it as an option.

Participants had mixed opinions about group care. Some saw great benefit in grouping the women together in order to save time by delivering the same information to multiple patients at once, giving women access to a support group, and letting the women learn from each other.

You get a group of people who are in a similar situation together and they can commiserate and fellowship and build each other up and share personal experiences and encourage each other. I think it's mutually beneficial for the older to the younger patients. – Tyler

I have some friends at Kaiser and that's where I trained in California. They say it works really well because, first of all, if you use a nurse practitioner or a regular nurse, even, if you're getting information, that saves a little more time for the doctors to do other things. – Dallas

However, providers were also concerned that they would lose the important one-onone relationship with their patients, and that patients might be reluctant to talk about very personal issues in front of a group.

We want that individual one-on-one care with the patient. If I come into a room this size with 15 pregnant ladies and talk about something they don't relate to, they're not

engaged with me. The relationship is the most important. We do one-on-one care." – San Antonio

### **Postpartum Care**

Participants were then asked questions about their routine practices in providing postpartum care, including the number of visits patients receive (or can receive), how often patients come to these visits, barriers they see to getting this care, what is discussed, whether they talk about birth spacing and birth control, and how they refer patients who need additional care.

Focus group participants said that, overall, the majority of women come to at least one postpartum visit.

Most of ours. I'd say 90%. - Dallas

I was going to say pretty good. [Patients say,] "I want the birth control." They're coming back. – Tyler

Unlike during prenatal visits, participants reported that few women are accompanied by a spouse or partner during their postpartum visits. For those that don't make their postpartum appointment at all, providers identified causes of still being tired or not wanting to travel with the baby.

They don't want to travel with the baby. They don't have anybody to keep the baby. We're like, "Well, bring them." Some of them just don't do it. Too worried. – Dallas

In an effort to encourage women to receive postpartum care and check in on how they are doing, many of the providers in these groups had a nurse or staff member follow up with patients by phone within three weeks of a birth, which ideally is followed by an in-office visit within six weeks.

When describing a typical postpartum visit, providers listed mental health as a primary concern and topic of discussion; some participants are following the new American College of Obstetricians and Gynecologists (ACOG) protocol of offering a postpartum visit at two weeks following the birth.

We do a two-week just the Edinburgh depression scale, just to see how mentally they're doing. -Tyler

The providers in these groups also include a focus on breastfeeding in the postpartum visit as well as a full range of physical issues as appropriate, including diabetes follow up, healing from delivery, mastitis, and birth control. They said most of their patients

are coming in overwhelmed with their first concern being how to get themselves and their babies to sleep.

We get their weight, blood pressure, urine. The nurse will usually ask them any problems they're having and are they breastfeeding or not. Then we come in and do a physical, mainly a uterine check. A big part of the visit is talking about contraception. "What are you going to do now? Don't count on breastfeeding. What's your plan? Is the baby sleeping?" and all that. – Dallas

I do breast exams, too.... just for mastitis check. I talk to them about their breastfeeding, too. – Dallas

If they had a C-section, you want to look at their incision, make sure it's healed nicely, make sure their bowel and bladder habits have returned to normal. Oftentimes they're having stress incontinence still at their postpartum visit, and encouraging them to know that that's very common, that's normal, educating them on Kegel exercises. – Tyler

When participants talked about postpartum care priorities and the topics they cover with their patients, they notably did not mention multivitamins with folic acid or healthy weight and nutrition.

As touched on earlier, the providers said that they often spoke to women about birth control during postpartum visits, and all reported that they talked about the importance of birth spacing with woman. However, none of them mentioned the specific timeframe recommended by the Centers for Disease Control and Prevention (CDC) of 18 to 24 months before becoming pregnant again. Instead, they spoke of a variety of times and the general need for women to wait longer and let their bodies recover from a pregnancy before starting a new pregnancy.

We always encourage some time. You should be on some kind of contraception so that their body can recover from this pregnancy. – Dallas

I usually encourage people to avoid pregnancy for a year after delivery because we know a short-term pregnancy interval increases the risk of preterm labor and preterm birth. I always tell them, "It's really best for you and your baby if you can have a year between pregnancies. It's a good time for your body to recover, especially if you breastfeed for that year. Get your body back to normal, to yourself, for a little while. – Tyler

I primarily would talk to them, maybe, if they ended up with a first C-section. Then I'm more likely inclined to tell them, "Please don't get pregnant right away because one year is to heal." You don't want this person coming back nine months later. - San Antonio

Participants were also asked how they would help a patient transition to in-patient care if it became necessary as a result of issues or symptoms in their postpartum visits. Providers stated that they would either call EMS or – if they felt it was safe for a patient to travel in a personal vehicle – call ahead to the hospital to warn them that a patient was coming.

If it's an emergent thing, usually I would call EMS, and then I would actually call the ER and I'd call the charge nurse and say, "Hey, this person's coming from my office to your ER, and this is what's going on." – Tyler

If it was an outpatient admission — like they come in postpartum and their blood pressure is in a severe range and they need to be admitted for postpartum preeclampsia, then I can send them in a personal vehicle if I don't think it's an emergency and I send an order. So, then I ask the admission unit to just page me when the patient arrived to the floor. We call the charge nurse in labor and delivery, and then whoever's on call takes over their care. – Tyler

# High Risk Care and Coordination

The providers in the focus groups were asked about high risk care, including the most common risk factors, which risk factors were most concerning to them, how well their patients tended to understand their conditions, how they handle referrals, and continuing care for these patients.

When asked about high risk care, providers identified the following as the most common risk factors:

- Obesity
- High blood pressure
- Diabetes
- Advanced maternal age

- Mental health
- HIV
- Asthma
- Drug use

Some providers said that patients with these conditions don't always come in early for care.

I had a 44-year-old, 305-pound, hypertensive, hypothyroid cerclage in the office today with no prenatal care that walked in at 23 weeks and lost her last baby in March at 23 weeks, and came in with no care. – Dallas

Of the conditions listed above that they commonly see, the providers most frequently identified obesity, hypertension, diabetes, mental health, and advanced maternal age as the most concerning factors to them.

I really do think that obesity is such a growing problem. The problem is, is it predisposes to all of that. It predisposes to the preeclampsia, it predisposes to diabetes, it predisposes to venous thromboembolism. I think it's also a hard conversation to have in a gentle, kind, encouraging way. – Dallas

Depending on how bad their diabetes is, it can lead to also vascular disease and all sorts of necropathies [tissue death or gangrene]. It puts them at increased risk for hypertensive complications as well. – Tyler

Gestational diabetes means just during their pregnancy, but once they're delivered, those folks are at higher risk of developing diabetes later in life. You need to check that with a two-hour, 75-gram glucose challenge, sometime after their pregnancy. – San Antonio

Other high risk would be middle age, ... With that, a lot of other morbidities occur, high blood pressure, gestational diabetes. – San Antonio

*Drug use and depression and antidepressants -* San Antonio

When working with women who have high-risk conditions and want to become pregnant, these providers said they try to make them aware of the risks.

If they're trying, I bring [prenatal vitamins] up to them. I also review their meds and make sure that there aren't any problems with the meds that they're on that might cause problems if she were to become pregnant. – Dallas

The providers consistently mentioned that many patients are uneducated about their own risk factors and health histories.

I would only say about 20% of the people really know what their risks are. Whether they have high blood pressure or not, they just know they have it, but they don't know — a lot of people don't know that they could have a stroke. It's amazing. I'll tell people, when they'll have a high blood pressure like 180/100. "Is that high?" I'm like, "I'm going to have to send you to ER." "Why?" "I don't want you to leave my office and have a stroke." — Dallas

To manage these conditions, providers most frequently refer pregnant clients to a maternal-fetal medicine specialist. However, access to these specialists can be a challenge in many areas and participants discussed this reality as well.

As previously mentioned, in many cases, providers do what they can to treat conditions themselves directly or collaboratively to improve patient access to care.

We handle almost all of the diabetes that we see. It's only rare that we have to use an endocrinologist and, usually, the endocrinologist can't control it either because it's the patient that is noncompliant. – Tyler

When transitioning patients from prenatal to ongoing general healthcare, many of the providers reported that they follow up postpartum and then refer to a primary care doctor or specialist to continue tracking women's high-risk conditions.

For six weeks, it's us. Then if we need a hospitalist or internist to see them, we'll consult them, but it's usually us. – Dallas

They usually have extra visits postpartum. Sometimes you're having to see them at two weeks, or weekly if you're weaning them off meds. – Dallas

To educate patients about continued care, physicians often provide pamphlets or refer patients to websites. Participants reported that they rarely review the resource with the patient during a visit.

## **Referral Networks and Experiences**

Referrals to specialists and care coordination are critical parts of treating high-risk patients at all stages of life – in the preconception, prenatal, and postpartum periods and beyond. It was clear from the responses that focus group participants gave during this discussion that the process of giving referrals, tracking referrals, and finding providers to refer to varies widely and depends on a number of factors.

Many of the providers indicated that they felt very close to their referral networks and had developed close relationships with these other providers and effective ways of working with them. Some of these relationships, however, require an informal network that takes time to build, so not all the providers had established those close relationships.

We have a group in Dallas that we work really closely with. I have their cell phone numbers and I can call them. I'll even sometimes call them in my clinic and say, "Hey, I've got this clinical scenario. I just need you to give me some advice. I need your blessing," basically. – Tyler

I've only lived here for four and a half years. Moving here, I just went straight to my office and I never had to do inpatient at the hospital, so I haven't been able to get out and

network with other providers because I'm in my little hole in the wall from eight to five Monday through Friday. Whereas previously, where I was for 13 years and had lived my entire life, I knew anybody and everybody. – Tyler

In Dallas, there seemed to be more distance between the providers and their referral networks.

The only people who are high risk that we really have good communications are the perinatologists. They do the sono; they send you a report. If there's some immediate problem, they call you. Or if they want to get the information or something like that. That's a direct communication, but everybody else [is not as communicative or coordinated]. – Dallas

Participants' indicated that they use referral coordinators more than patient navigators to help with referrals. Many of them had a referral coordinator in their practice. Others just used their office manager or secretary to fill this role. Providers in Tyler were asked about using patient navigators, and none of them knew what that term meant.

The referral coordinator, that's one of her jobs, is to follow back up and make sure. We send a referral, and their job is to make sure we get a note back from that referring physician. – Tyler

We have a referral coordinator that we send if they have insurance where they need a referral. – Dallas

Providers were clear in their discussions that they have an easier time with referrals and continuity of care when they were working in a large hospital-based organization or HMO where providers share the same electronic medical records (EMR) system and have resources to track referrals. Providers mentioned that the Affordable Care Act required doctor's offices to use EMR systems, but the EMR systems don't always talk to each other, so there's no straightforward way for doctors in separate practices to share information.

When I was with Kaiser, it was a different story because we were all under this umbrella. We all had unified EMR. They went to the urologist. She came back. Poof, there's her thing. She went to the psychiatrist. I can pull the note. Everything was there. It was easy. – San Antonio

The problem was, when the government mandated all that, they didn't make it that every EMR will talk to each other and deposit all those visits. – San Antonio

Providers in the groups also reported how managed care insurance requirements pose a problem for those in private practice to provide referrals. Both Medicaid and Blue

Cross/Blue Shield HMO plans, for example, may have a network of independent providers who work together under the same umbrella, yet seeing a specialist requires referrals from a primary care physician (PCP). So, if a woman has a high-risk pregnancy and her OB/GYN needs to refer her to another specialist, she must first make an appointment with her PCP for that referral. However, participants stated that their patients don't necessarily have a PCP and may have to find one just for that referral so the whole process becomes a barrier.

I had somebody that needed to go see a fetal surgeon in Houston. She didn't have a primary doctor, and I had to establish her with a primary care doctor to get the referral to the fetal surgeon in Houston. – Tyler

I have to send them to their primary care doctor to get a referral to the high-risk OB specialist in Dallas or Houston. The primary care doctor doesn't see cystic hygromas on babies, and they're having to do the referral. In some of these patients, like we've said before, don't even have a primary care doctor, so then we have to find them a primary care doctor to go say, "Hi, nice to meet you. Can you give me a referral to a high-risk OB specialist?" – Tyler

This type of referral process also affects the likelihood of follow up. Participants stated that, if a patient is referred for a less critical treatment, it is unlikely that the specialist is going to report back to the referring physician. Participants also indicated that, if a patient is being referred for psychiatric care, privacy standards may prevent the psychiatrist from sharing information.

If a lady has a breast mass, you're going to refer to the general surgeon for excision or whatever. You're very concerned about that patient. That patient is going to be closely followed. The general surgeon may even call you and say, "Look, this lady has breast cancer. We need to do X, Y and Z." They're going to send you a letter. Contrast that with an 18-year-old, young lady who comes in with acne. You say, "I'm going to refer you to the dermatologist." You're not going to get that conversation with a dermatologist because they don't see it as a consult. They see it as refer and treat. – San Antonio

Providers in the focus groups also reported that it is a challenge to find physicians who will take patients with Medicaid. They said this causes many patients to seek care only in the emergency room and has caused dangerous medical issues.

The nearest rheumatologist for a Medicaid patient is close to 45 miles, close to Austin. – San Antonio

There's not a lot of services for Medicaid patients in any specialty. You want to refer them somewhere, there's just not a lot of services. – Dallas We have to, generally, send [Medicaid patients] to the ER. Say if they're having hypertensive crisis, no doctor will take them. No doctor on campus will see them. They have to either go through the Medicaid referral, which our OB coordinator does, which may take up to two months, or you just send them to the ER, and then people are forced to see them. – Dallas

I had a [Medicaid] patient who had diabetes really out of control. She had a miscarriage. I could just send her to the ER for follow-up. Her blood sugar was two-something, but nobody would take her. – Dallas

It's hard to find a Medicaid person to send them for nutritional battery consult. It's very difficult to find. – San Antonio

Participants also described how, in rural areas of Texas, geography creates a barrier to care. There may not be enough local resources and providers, which forces patients to travel a longer distance to access care. Travel can be a challenge for lower income clients even in larger cities who may not have access to transportation, or may not have the ability to leave work to go see the specialist.

We refer to maternal-fetal medicine, but we don't have one in East Texas. - Tyler

A lot of my referrals, I was trying to send people to downtown Dallas, and they're like, "I'm not driving down there. I haven't been down there in 30 years." – Dallas

Finally, the providers discussed how one issue in getting a successful referral is the patient themselves. Patients may not show up for a referral appointment for a variety of reasons.

I can't drive them there. I can't pick them up, take them to their PCP, and push them in the door. I think there has to be — you have a responsibility to bring it to their attention. You have a responsibility that you document that you're concerned about it and that you're recommending that they follow the recommendation. — San Antonio

I think there's still the stigma with it, too, makes people not want to go. "I don't need to go see a psychiatrist." - Dallas

I have to explain to them the severity and the importance of them having to go and pay \$200 or \$300 to see a cardiologist or something like that. I have to explain everything and how this is going to benefit them in the long term, like prevent a heart attack or prevent something further. I've had some good response as far as they will come up with the money to go and then some of them were like, "Hmm." – Tyler

The problem mostly happens ...with those who are socially at a disadvantage, persons like Medicaid and the drug users, they don't want to see a doctor. – San Antonio

# **Community Connections**

In general, when moderators asked the providers how connected they felt to other community resources that could help women, participants generally didn't see it as their job to make these connections. They stated that it was more the job of hospital case managers to refer patients to community resources.

*Not in the primary care office. Hospital – they have very good case managers. They are support. –* San Antonio

I don't think the providers, per se, are connected, but our referral clerks and our health workers are connected very closely. – Tyler

In many cases, the providers expressed opinions that community resources were limited or ineffective at addressing their patient's high-risk conditions.

There's a battered women's shelter. There's all kind of resources for that or rape crisis, things of that nature for abused women. That is something that — it's easy for me to get them hooked into that, but somebody who has diabetes or has hypertension, there's no battered women's center for hypertensive women." — San Antonio

A lot of times we'll consult social work if you know they're having a difficult social situation or drug use. I just feel like they don't do anything for them. – Dallas

Despite this, many providers still do recommend community services to their patients as applicable when they know about them.

When I do have a Medicaid OB, I will ask them, "Do you know about WIC yet?" - Tyler

Most of the time [patients needing mental health services] end up at Metrocare... It's the MHMR here. – Dallas

If we think somebody is truly harmful to their self or others, a couple blocks over we have ACCESS...they will actually come to your clinic and do intake right there. – Tyler

H-E-B has a nutritionist service that they offer. It's good for the price. - San Antonio

#### **Patient Education**

Many of the providers in these groups continue to use pamphlets – primarily from ACOG – to help educate their patients on health-related issues, options, and conditions.

I give handouts a lot. I'm still old school like that. I have the ACOG contraceptive education thing that's geared for teenagers. – Dallas

I think probably most everybody has handouts that they give patients covering all those issues. From that standpoint, I think we have that pretty well-covered. Most of the stuff that I use comes from ACOG. I think they do a very good job when it comes to their pamphlets that are available. – Tyler

[ACOG] and the State of Texas has things that they'll send out that you can put on your board – vaccines, for example, and things like that that they can take home with them. – San Antonio

In addition, participants stated that more and more providers are turning to internet resources (sometimes even creating their own) for patient education.

We have brochures that have websites that they can refer to. - Dallas

With our office, it is established as a Catholic-based facility, so we don't have birth control brochures in our office. I have to give them a generic website to go to or something like that. – Tyler

People say, "We love your podcast. We're listening to them." It's a nice way to get information out there. – San Antonio

However, in the end, providers reported that they see one-to-one education offered in a language that matched the patient's education level as a critical tool with high risk clients.

I think one of the things that we have found in my 20-year practice is engagement, engaging the patient. I was hanging fliers, but it did no good. If I want to discuss all their particular problems, rather than just prescribing medicine, I get them involved in why we are doing what we are doing. Some of them are science in basic terms in a way they can understand. ... Talking to them is the key. – San Antonio

Communication is a very big thing in lower socioeconomic classes, dealing with what level of education they're on to understand what you're even telling them. – Tyler

# **One Key Question**

As mentioned earlier in this report, the One Key Question® initiative encourages all primary care health teams to routinely ask women of reproductive-age, "Would you like to become pregnant in the next year?" with the goal of proactively addressing the root causes of poor birth outcomes and disparities in maternal and infant health. Providers then can offer follow-up preventive reproductive health services depending on patient needs. This initiative is being used in some locations around Texas, so participants were asked about it to determine their reaction and preferences. Providers were shown the website (www.onekeyquestion.org), asked about their familiarity with the initiative and approach, and asked if or how they would use it in their practice.

The majority of these providers were not aware of the One Key Question approach before this focus group. When asked if they knew about it, the general answer was a room full of shaking heads, or a flat out no.

I'm embarrassed that I haven't heard of it. - San Antonio

The only one participant already familiar with the concept of One Key Question had learned about it from ACOG.

ACOG has endorsed it. .... They've talked about it a lot. - San Antonio

Despite the unfamiliarity with the One Key Question initiative itself, many participants stated that they were using its underlying concepts in their practice already.

*We don't use those exact words, but we do ask that. -* Tyler

I think it's our job. Every day we go over it. - Dallas

Participants who did not exclusively provide OB/GYN care expressed opinions that the campaign should target primary care physicians who may not be thinking about reproductive health as their first or key question during patient visits with those of reproductive age.

I think this would be great in other primary cares. I'll be honest, this isn't on my checklist of things that I do. Now it will be. - Dallas

I find that a lot of primary care doctors – patients that come to me from other primary care doctors never got asked those questions. - San Antonio

Some of these providers – particularly those working in larger HMO or health organizations - reported that they work with EMR systems that have pre-programmed questions to guide a well woman exam. While they are not constrained by these questions, and may skip them or go off script, they do rely on them to guide the pace of their exams and often try to make sure they ask all of them in each exam. These participants recommended an effort to embed the One Key Question into these EMR systems to make sure providers are using it consistently.

Your EMR has a lot of those questions already on there. I try to fill in all the blanks. You get around to [this question] sooner or later, in doing that. - San Antonio

## **Materials Testing**

Toward the end of each focus group, participants had the opportunity to review a few key patient education resources and provide feedback on the style, content, and provider ordering options.

### **Power Your Family Pamphlet**

This pamphlet, among other things, offers specific information, timelines/guidelines, and risk factors related to pregnancy spacing. Additional information on this resource is in the Materials Description section earlier in the report. Provider reactions to it were positive overall.

Power Me A@Z

I feel like it gives the woman the feeling like they have the power to decide what they want. - Tyler

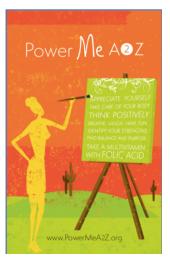
"When will I be ready again, if ever?" Think about these different areas. This might be good on a postpartum visit so they know." - Dallas

Some participants thought the information would be more helpful if it was in an app or available online.

We have touchscreen wallboards in our exam room that rotate through different informational pieces. ... Patients like that a lot better than handouts because they actually engage with the wallboard. - San Antonio

As previously mentioned, providers in the focus groups don't typically give their patients specific recommended birth spacing timeframes following public health best practices guidelines. This pamphlet - or the content used in another medium - would fill a gap in current postpartum conversations about birth spacing that is currently missing.

#### PowerMeA2Z - Health Resource Order Form



Providers were shown the *PowerMeA2Z* website from Arizona and directed to a portal where providers could order information, such as pamphlets that they could share with their patients. Then they were asked whether they would be interested in a similar web resource that would provide resources for them as well as a website that they could direct patients to.

Overall, participants expressed the opinion that having both a web resource and matching pamphlets would be a good idea for their clients, and that they would be likely to share such a resource.

*I like the resource.* – Tyler

I think if you could have both it would be good because some people — I'm thinking more like the refugees — may not access to all this technology. — Dallas

When asked if they would go to a portal like this to order pamphlets, the providers uniformly said that they would.

Yes. - Dallas

*I like the fact that you do get some in Spanish.* – Tyler

Sure. - San Antonio

# **Information Sources and Marketing to Providers**

When asked how they wanted to get more information about resources they could share with their patients, participants had a variety of answers.

They feel that they are already overwhelmed with email marketing, so they prefer that all email marketing come through their hospital system or a professional organization that they already use for information.

If you email, we get so much email. How much time do you have to read about that? It almost might be better if you send a blast through your hospital to the physicians on the staff, and then maybe have that discussion at one of our departmental meetings.

- San Antonio

It's like the Smith County Medical Society. They could get email blasts out to all the doctors. - Tyler

At medical meetings or ACOG meeting or our local DOG meeting. - San Antonio

Most also wanted someone to drop off information in person to their offices and speak to a key staff member when doing so or mail it through a professional organization.

Ask to talk to the manager or one of the lead nurses or somebody. Not just drop it at the front because you might not ever get to read that. - Tyler

*Come by the office. Put something in the mail. – San Antonio* 

### Conclusion

The providers in these focus groups expressed great commitment to improving women's health and reproductive health. Many of the them gave examples of their personal dedication to try to reduce barriers to care: offering gas cards, educational videos, finding community resources for low-cost birth control, and even personally driving a client to an appointment. They also support patients' access to care by providing some standard services outside of their specialty area (e.g., routine bloodwork) and coordination for referrals.

Participants knew that the majority of their patients are unaware of their own health histories and lack education and understanding of their health issues. For providers in private practice, this creates a substantial barrier to providing effective care for patients with high-risk conditions. Additionally, these providers often use informal, personal referral networks with specialists who may not check back in with them or may not be able to share records easily, so tracking patient information and care becomes challenging. Participants indicated that this is less of a barrier for providers working in an HMO or hospital-based practice with shared EMR systems.

Medicaid itself is a barrier to care for many of these providers' clients. Between a limited set of providers that accept Medicaid and the amount of time it takes to get approved for Medicaid when pregnant as well as the short postpartum duration that Medicaid covers, providers stated that many women, especially those with high-risk conditions, are not getting needed care to ensure a healthy pregnancy and delivery and adequate condition management following childbirth.

Mental health concerns, primarily anxiety and depression, are among the most – if not the single most -- common issue that these providers see in their patients and practices. In many cases, providers have limited referral resources for mental health support and are seeking creative ways to offer treatment to patients.

These providers are talking to their patients about birth control and family planning as part of well woman and postpartum visits. However, their responses indicated that they are not using the formal CDC recommendations for birth spacing or One Key Question program to guide and structure these discussions.

When presented with materials to help support these reproductive health conversations, participants responded positively and said they would welcome more effective materials (print, online, and apps) for guiding their patient education and interactions. Similar to what they know to be effective in engaging their patients, they recommended that marketing to their practices be through one-on-one outreach and visits or through a trusted source or organization.

# Coalition Members and Key Stakeholders

## Background, Goals, and Participants

As part of its formative research, SUMA conducted in-depth phone interviews in October and November 2018 with 10 key stakeholders as well as with 15 representatives from coalitions in the nine communities across the state that were awarded Texas Department of State Health Services (DSHS) grants to implement interventions to improve women's and children's health in their communities.

The goals of the coalition and stakeholder interviews were to:

- Provide background information and context for the SUMA research team, including to inform the subsequent focus group research.
- Collect various perspectives about unmet needs and priorities.
- ♦ Identify opportunities for DSHS to support coalitions and stakeholders with a campaign, messages, tools, and other resources as well as by fostering networking and collaboration.

The interviews with coalition members also explored the level of maturity of each coalition and their progress toward identifying local priority populations and key messages.

The guides for the coalition and stakeholder interviews are included in the Appendix. During the interviews, the researchers took extensive notes, to the extent possible, capturing the participants' comments verbatim. Indented, italicized text in this section represents quotes taken from the notes.

Interview participants represented coalitions in the following cities or counties:

- ♦ Amarillo
- Brownsville
- ♦ Dallas
- ♦ Laredo
- ♦ Port Arthur
- San Antonio
- ◆ Tarrant County
- ♦ Tyler
- ♦ Waco

DSHS staff provided contact information for the leader of each coalition receiving a grant, and SUMA researchers interviewed these nine representatives first. In six cases, based on a recommendation from the coalition leader, a second person from the community was interviewed. Some of the participants in the second round of interviews represented the same agency as the leader; others were community partners.

The stakeholders included three clinicians (one OB/GYNs who sees a diverse population; one OB/GYN who specializes in women with high-risk pregnancies; and a hospital nurse who provides postpartum care, including breastfeeding support), as well as professionals involved with: Healthy Start, WIC, fatherhood programming, health education at a university, DSHS regional programming, and research and data related to women's and children's health.

The findings in this section reflect an analysis of the interview research notes as well as verbatim quotes from participants. Since the lines of inquiry for coalition members and stakeholders overlapped, the findings from interviews with the two groups have been integrated and are presented below.

### **Detailed Findings**

## **Coalition Stages of Development**

SUMA researchers asked the representatives of the coalitions how and when the group was formed, how it is structured, and the group's biggest successes and challenges so far. Their responses illustrated three distinct stages of coalition development.

At the time of the interviews, three of the community coalitions were in the very beginning stages of development. The **Amarillo** and **Port Arthur** coalitions were reaching out to partners and assessing community needs. **Brownsville** had not yet received the grant funding.

Representatives from five coalitions described their group as in a transition phase or evolving. At the time of the interviews, they were all working to establish their identities and cultures. Four of these were building on an existing community coalition or collaboration, and working to use the resources from the DSHS grant to focus more intensely on women's and children's health. The fifth, **Tyler**, was transitioning from a dependence on leadership from grant-funded staff to sharing leadership roles with community partners. A few details about each of their circumstances follow.

◆ **Dallas:** Dallas coalition leaders described how they are building on an existing community action network. This group had historically functioned as a

consortium, an alliance of organizations focusing on high-level strategic or policy decisions. Attendance at meetings was inconsistent, with different people showing up each month, which made it difficult to sustain any momentum. Moving forward, coalition leaders hope to transition the network to a more engaged group organized around action. They hired a coalition coordinator two weeks before the interviews took place, and also have hired an independent facilitator to conduct strategic planning with the 40 agencies involved.

- ♦ San Antonio: At the time of the interviews, San Antonio Health Department staff were planning to hire a coalition coordinator to take the existing Healthy Family Network, a collaboration of over 30 organizations working on improving pregnancy and birth outcomes, to the next level. They also expressed a desire to move forward in a more action-oriented way in the community.
- ◆ Tarrant County: The Tarrant County coalition is building on the 17-year-old Infant Health Network. Tarrant County Public Health leaders have applied for nonprofit status for the coalition and hope the DSHS grant will allow the group to apply for additional grants and hire administrative support. One of the group's biggest organizational challenges thus far has been finding people willing to take on leadership roles.
- ◆ Laredo: Under a previous Healthy Texas Babies grant from 2009-2012, grantfunded staff joined forces with the existing Laredo Health Coalition. At the time of these interviews, the coalition coordinator was continuing to raise awareness about infant mortality among the more than 40 members of this group and providing information about clinic services available through the City of Laredo Health Department.
- ◆ Tyler: Upon receiving the DSHS funding, the Tyler coalition hired a full-time Healthy Me Healthy Babies Coalition program specialist. When she decided to shift to a part-time schedule, the coalition faced a challenge as it was highly dependent on her leadership and support. Community partners decided to hold two separate strategic planning sessions, one to address the coalition's structure and operations, and a second session to focus on a community needs assessment. As part of the process, community members stepped up to fill the leadership roles, exemplifying how a coalition can move from staff-directed coordination to collective action.

A lot of things came out of that [first strategic planning] meeting. The community partners did not want Net Health, the grant administrator, to be the leadership for the coalition... They said, "Fine, you got the grant, but you

shouldn't be running it. We need to do spring cleaning and revamp how we are meeting and what we are doing. No workgroups until after the second strategic planning meeting. And we want the things we do to be voted on by coalition members."

The Prevention Institute describes a strong coalition as one that has "a heightened sense of collective identity and a high degree of interest in and commitment to work which is developed collaboratively." Based on that criteria, the coalition in **Waco** is the most advanced of the nine coalitions. In 2016, the local health department and two community foundations hired SUMA to conduct research and facilitate the beginning of a community coalition around women's health. At that time, members of the budding coalition agreed to promote annual wellness exams for women who have not had a baby. With continued local financial support, the coalition has engaged partners, developed a detailed strategic plan, and is making progress toward its agreed-upon goals.

## **Coalition Strategic Priorities**

When asked about their coalition's strategic priorities, many participants described their own organization's priorities or those of their position within that organization. In some cases, this was because the coalition had not yet developed shared priorities or goals based on data from a community needs assessment, and did not have a structure in place for collective decision-making. Across the coalitions, the stated priorities included:

- Promoting life planning for young women, preferably adolescents
- Raising awareness about maternal and child health and decreasing infant mortality
- Improving pregnancy and birth outcomes
- Access to prenatal care
- Preconception health
- Focusing on the social determinants of health
- ♦ Testing for STDs
- Workforce development
- Getting the word out about the coalition's work to our partners in the community

<sup>&</sup>lt;sup>1</sup> Cohen L, Baer N, Satterwhite P. (2002). Developing effective coalitions: An eight step guide. Prevention Institute. p. 22. Retrieved from: https://www.preventioninstitute.org/sites/default/files/uploads/8steps 040511 WEB.pdf

The understanding of addressing "maternal and child health" varied greatly among coalition members who participated in interviews. At one end of the spectrum, participants cited the importance of considering the social determinants of health, noting that broader efforts such as increasing employment opportunities and helping people access housing and social services are keys to improving health outcomes. At the other end of the spectrum, one person believed that only a very focused effort would "count," excluding even efforts to address obesity and diabetes, which are known to put pregnant women and their babies at significant risk.

We have March of Dimes, United Way, and some local community health worker initiatives, but those are ending. We have the school of public health, working mostly on diabetes and obesity, not on maternal and child health.

## **Coalition Priority Populations**

When asked about their coalition's priority population or populations, many participants again described their own organization's priorities. Priorities varied significantly across the nine communities and differed widely in terms of specificity. Some of the categories reported were so broad that they cannot accurately be defined as specific populations. The responses were as follows:

- ♦ Low income women and teens
- Adolescent women
- Women and men
- ◆ Young African-American mothers, Hispanic/Latina women, men, women who have not had a baby, and/or women in the WIC program
- Families, pregnant women, and infants in the first year of life
- Women of childbearing age (18 to 44 years) and their families
- ♦ Women (18 to 40 years), with a particular focus on women 13 to 27 years and African-American women
- ◆ Parents and women before pregnancy
- ◆ Women (18 to 25 years) and providers at the local Federally Qualified Health Center (FQHC)

Most of the participants said they were too early in the planning stage to have learned much about their priority population(s). Exceptions included:

- ◆ Tarrant County, where data have shown a high rate of infant deaths connected to preterm delivery because of STDs.
- Amarillo, where focus group findings indicated that teen mothers lacked knowledge about contraception and lacked access to people knowledgeable about it.
- Waco, where previous focus group research helped the coalition identify the messages and channels most likely to reach the preconception population.

Some participants indicated that their coalitions are planning to do research to learn more about their priority populations. For example, the Port Arthur coalition plans to conduct focus groups to learn why mothers do not get to medical appointments, why women do not get prenatal care, and to identify the barriers to safe sleep. The Waco coalition intends to do research to identify the barriers to prenatal visits, and find out more about teens and pregnancy. The most frequently mentioned barrier to learning more about local priority populations was the challenge of accessing data. Barriers ranged from basic to very complicated.

Vital Stats is housed in the health department, but she told me they don't have access to the information we need. Our Epidemiologist is focused on public health emergency preparedness and doesn't do what we need for the stats for the needs assessment. I reached out to everyone they [DSHS] told me to and didn't get very far.

It's hard to get state level data - birth and death records - we do get them at a local level but if we want data cohorts to do trending, that's hard. For MMR [maternal mortality rate] data, the numbers are so small. Local health departments are not in the group that has access to state data. In some ways the issue is legislative, but we are trying to work with the Vital Records Office at the state level. First, they said we would have to go to the IRB [institutional review board] to get records, even as a local health department. Now we are trying to do a contract with the state, but we have been working three years to make that happen. Sometimes we get a data summary. We can use it for internal planning but can't publish it or share it with coalition members. For example, we have data from birth certificates linked to two zip codes — an incident code and an occurrence code. We are not allowed to make public the data set for residences. But we can't know where to target based on the hospital zip codes.

### **Coalition Calls to Action**

At the time of the interviews, many of the coalitions were just beginning to identify their priority goals and calls to action, even some of the coalitions that are building on established and long-term groups. Representatives from five of the nine communities were able to articulate a call or multiple calls to action, and to provide some details about their outreach and engagement strategies. Yet again, some seemed to be speaking from the perspective of their own organizations, not the perspective of the coalition. It is unclear how many of the coalitions have a collective decision-making process in place.

#### ♦ Laredo

• Get a wellness checkup (women and men). The Laredo Health Department promotes its own Title V clinic services at health fairs, through charging stations, and on billboards. The department promotes women's wellness through social media (Facebook, Twitter, Instagram and Snapchat) and outreach events. Staff promote literature from the health department's clinic, which seems to work well with women. They recommend Bedsider.org for information about birth control. Staff are not satisfied with materials or outreach to men.

#### ♦ San Antonio

• Get early prenatal care. Safe sleep. Increase postpartum visits. The health department has partnered with two healthcare systems to pilot a prenatal care toolkit in collaboration with the local March of Dimes chapter. In the past, the department conducted a media campaign promoting prenatal care that included billboards, radio, and social media, but this effort did not increase the volume of women seeking prenatal care as much as they had hoped. The coalition is starting to distribute safe sleep toolkits through the health department and local partners, and is working on developing refrigerator magnets to promote postpartum visits.

#### ♦ Northeast Texas

• Get prenatal care. Don't smoke. Have a healthy lifestyle. Go to postpartum appointments. The FQHC has implemented a policy of default group prenatal care, where women have to opt out of (instead of opting in

- to) receiving prenatal care in a cohort model<sup>2</sup> in group sessions with other pregnant women.
- FQHC staff also: participate in health fairs; conduct outreach at apartments, churches, and daycares; post on Facebook; and reach out to non-traditional partners such as fire departments, police departments, and barber/beauty shops. WIC staff participate in health fairs and events, distribute swag bags with literature (including a reproductive life planning tool), and have developed talking points to use at barber shops.

## **♦** Tarrant County

• Help women age 18 to 44 achieve their fullest potential by 2022. The coalition is focusing on two paths to achieve this goal: STD education and testing; and job referrals, education, and vocational training. They have developed push cards in English and Spanish for each path as well as an elevator speech to help partners talk to women about STDs.

#### ♦ Waco

• Women in preconception stage of life: get an annual wellness exam. Providers: ask the One Key Question. The Waco coalition has developed a website for women and engaged community partners to promote annual wellness exams. To address preconception health, teen pregnancy, and interconception health, coalition members are educating healthcare providers about and promoting the use of One Key Question®. With this model, providers ask, "Would you like to become pregnant in the next year?" and based on the woman's answer, take her lead on the rest of the conversation, whether that is to discuss family planning, preconception health, prenatal care, or other needs. The coalition hopes to focus next on prenatal care and learn more about how to reduce teen pregnancy rates.

#### **Stakeholder Goals and Priorities**

The three stakeholders in clinical positions all reported that their work is dedicated to increasing positive birth outcomes, reducing maternal morbidity and mortality, and

<sup>&</sup>lt;sup>2</sup> The Centering Healthcare Institute describes one such model: "Centering group prenatal care follows the recommended schedule of 10 prenatal visits, but each visit is 90 minutes to two hours long - giving women 10x more time with their provider. Moms engage in their care by taking their own weight and blood pressure and recording their own health data with private time with their provider for belly check." More information at: <a href="https://www.centeringhealthcare.org">https://www.centeringhealthcare.org</a>

reducing infant mortality. The other stakeholders are involved in programs and, depending on their individual role and area of expertise, they articulated the following priorities and desired outcomes for those they serve or reach:

- Healthy lifestyle choices
- Pregnancy planning and spacing
- ♦ Early prenatal care
- Optimal nutrition for pregnant/postpartum women and babies
- Breastfeeding
- ♦ Safe sleep
- ♦ Connections between fathers and children

Identified priority populations varied greatly across the stakeholders and, as with the coalition members, participant responses reflected different ideas of what "priority population" means. For example, one stakeholder identified seven broad audiences as priority populations, illustrating a lack of understanding of the concept. The following were mentioned by one or more stakeholders as priority populations:

- ♦ Women of childbearing age
- ♦ Women who are pregnant
- Women who are pregnant or who have a child under age two
- Women who are not pregnant
- Mothers
- ♦ Fathers
- Children up to two years old
- ♦ Refugee populations
- Residents of colonias (unincorporated areas along the Mexico border where families in poverty live, typically without access to public utilities)
- Women of color
- College students
- Teen fathers
- ♦ All families at all income levels
- ♦ Low income families

### **Perceived Barriers and Unmet Needs**

The researchers asked the ten stakeholders what they perceived as the biggest barriers to optimal health for women and children. Although this question was not a direct line of inquiry for the coalition members, some of them also identified barriers women face in their communities. The ideas from coalition members and stakeholders are incorporated below.

Across the board, access to care was the most frequently cited barrier. Several participants said cost is the primary reason women do not access care.

Healthcare is so expensive. Many can't afford it. There has to be a funding source. Expand Medicaid to a year after birth.

Participants also pointed to other factors that can limit access to care. Some said many women are unaware of affordable options or do not know how to access them.

There is a lack of awareness about what is available, for example, Healthy Texas Women.

The resources may be there, but we are not connecting moms with them effectively. They don't know about them. Texas has an embarrassment of riches for breastfeeding, so many trained professionals and staff, but the moms don't know about them. The doctors don't know about them.

A few participants said women may not access care because of a complicated or inefficient eligibility/enrollment process.

Sometimes it is hard to apply for insurance, getting all the documents together. They have limited computer skills to do the application.

I think the Texas Women's Health Program is great if you are not going to have full coverage [elsewhere]. There should be automatic enrollment. It is supposed to be but people aren't being auto-enrolled. There aren't enough providers. Or a name is on the list but the provider doesn't participate. The program needs expanding.

The state could work on eligibility to see what would help women get into a practice. Educate all providers who take Medicaid that there is presumptive eligibility, back pay, so women don't have to wait. Providers think presumptive eligibility is only for FQHCs or hospital systems. Go ahead and see her now – you will get reimbursed.

A few participants said women lose access to care after their child's birth because no one transitions them from their OB/GYN to a primary care physician.

They go to a private Medicaid provider who has no interest or incentive to help the mom once she has delivered. She may have hypertension, diabetes, almost die, but the OB/BYN



is done with her. These doctors want the women to come back to them, they want women on Medicaid, but when the women come back, they see that their chronic disease issues haven't been managed.

Private providers don't see linkage to care as their responsibility.

A few noted that a disconnect between providers and patients that can discourage women from accessing care.

When people go in for care, are clinics open, friendly, and listening?

Research has shown patients seem more confident with people they can relate to. There is a huge gap in diversity of care providers: doctors, nurses, doulas, every level of care. About 11-15% of the population is African American. Healthcare providers are not near that percentage.

Other barriers to access include perceptions that women's health is not important or worth speaking up about.

Part of the issue is what women see as important. I've been shaped by my world with access to healthcare. Others who don't have the money to access it don't think it is important.

They don't know about postpartum warning signs. Don't understand you have to overcome insecurity of covering up if you think you have a problem. They think, "Oh, that's normal." They don't know they have rights, what to look for, that it might be dangerous.

The clinician who serves women with high-risk pregnancies discussed how many women do not get appropriate care because they are not aware of their risk factors. Even those who do understand their risks can have limited options for accessing care.

Some women don't know they are at high risk for a future pregnancy. They are not aware of some health risk or occurrences in the past that have put them at risk in a future pregnancy... We can prevent preeclampsia and preterm birth, but they have to come see me before 35 weeks... We hear cases of women who die. Their family had known about the complaints for weeks. The woman might have mentioned it, but didn't talk about it again when it got worse.

For women on Medicaid, access to care is a challenge...It's hard for a midwife or a doctor to get the patient to see a doctor for high risk. For example, we don't take her type of Medicaid. Women have to switch providers, sometimes changing care mid-pregnancy. Some of the Medicaid plans don't cover well so some hospitals decide not to accept that plan.

Two stakeholders from one community said women may be eligible for more affordable or more comprehensive services but reject those options because they believe the care is of lesser quality.

No one wants to feel they are getting "less than" someone else. People don't want to go to the county hospital or the FQHC. Both of those settings have more integrated and more comprehensive care than a private doctor, but there is a stigma attached—that's where poor people go.

The Houston Endowment did a study on maternal mortality and morbidity. They did focus groups and found that more women prefer private providers to a clinic. They think the clinic is less likely to meet their needs.

Beyond access to care, participants identified some systems-level and cultural/social issues they believe have a negative impact on women's health. One clinician pointed to an overuse of C-sections that puts women and babies at higher risk.

Until the doctors are on board with evidence-based practices, we can only suggest things. The doctor sees a healthy mom and a healthy baby, so what's the problem? The C-section was rushed...50% get C-sections.

A few interview participants said that successfully addressing women's and children's health challenges involves tackling bigger societal issues.

...the social determinants of health. We need to make sure everyone is on the same page as to the elements affecting health. The family you are born into affects your schools and other resources, whether you have a safe place to play, food. So, if someone is engaging in behavior, you don't say, "What is wrong with them?" You say. "What happened to them?"

One stakeholder said general discomfort with breastfeeding in public discourages many women from doing what is best for their baby. That will not change until breastfeeding is normalized. This stakeholder believes that mothers need to be educated about their legal rights and healthcare professionals need to be educated about the many available resources to help mothers breastfeed successfully.

Finally, a few stakeholders mentioned the negative impact of implicit or unconscious bias among healthcare providers as a factor in health outcomes, particularly for African Americans.

We need to start talking about implicit bias...It's at the core of health issues for African Americans .... When you peel away every other driver and control for factors, these

women's outcomes are worse. We have to stop hiding and address it. Once it is in the open, it is easier to acknowledge.

For any health indicator, preterm birth, obesity, maternal morbidity and mortality, you see African Americans with the highest rates. It goes beyond education and economics. There is healthcare provider bias. They treat African-American patients differently than white patients. Race equity has to be taken into consideration. Get to the heart of that.

# Considerations for a State Campaign and Resources

SUMA researchers asked coalition members and stakeholders to describe an ideal Healthy Mothers Healthy Babies public health campaign. What messages would be the most important in their community? Who would the campaign target? What overarching message would be most important at the state level? What kind of campaign resources or materials would be the most helpful for local coalitions and stakeholders?

No single message or audience rose to the top; however, several categories of messages were mentioned frequently. A number of participants recommended messages related to self-esteem and empowerment:

- Everyone has value, a place. Everyone has a contribution to make.
- All lives matter.
- Have your list of questions ready for the doctor.
- If you start asking questions, providers will pay attention.

Participants who suggested these messages said women would be an obvious target audience.

Educate the mothers. Empower them. Give them knowledge. Tell them to have their list of questions in front of them when they go to the doctor.

Target those who could most benefit from the message. Target African-American women. And there is evidence to show that Hispanic infant mortality rates are increasing. You have to be careful not to stigmatize. The message is: you are worthy, valued. A self-empowerment message is more important than a health message. Go to your well woman check-up because the community needs you as a woman first, then as a mother. These populations haven't felt valued, worthy, or important.

A few participants said that healthcare providers need to hear messages about selfesteem and empowerment as well. The message is ...your patients are worthy, valuable. If you just focus on a small part of their life, you miss it. You have to look at the whole woman.

Target physicians who interact with women. Get across the message that women need to be listened to and that their experience matters...Look at the whole woman, not just one aspect. Make sure the time she spends with you is meaningful for her, and tailored to her needs, rather than cookie-cutter.

The researchers explored patient self-esteem and self-advocacy a bit more deeply with the clinicians, who said that white women, women who are insured, Hispanic women or their family members, and women who understand they are at high risk are the most likely to advocate for themselves. Conversely, African-American women, women who are unaware of their risks, and women who put 100% trust in their providers are least likely to advocate for themselves.

When the clinician participants were asked if they had found ways to help women speak up for themselves, one said no and the other said yes.

I haven't found any ways to help women speak up. It's hard. We see hundreds of patients in a month with contractions. Only a small number have complications. We get desensitized.

When women are not speaking up for themselves, I have to ask more questions...I was taught to ask open-ended questions, but if the person is not sophisticated or empowered, or if she is intimidated by the medical community, that doesn't work. I've felt it myself... I remember asking for birth control when I was young and being told, "I don't believe in that," and not saying anything and leaving. So, if I want to know if you have a headache, I will ask. Or I will ask, "What's going on at home?" And then sometimes the answers don't fit neatly into what we think of as the constraints of medicine.

A second category of commonly suggested campaign messages related to general health and wellness:

- Be healthy, mentally, emotionally, and physically throughout your life.
- Make healthy choices because it all matters.
- ♦ Health matters; a healthy you
- ♦ Take care of your body.

# Opinions varied as to the best audience(s) for these messages:

Target anyone of reproductive age with tools and resources that are readily available, low literacy info. And a more professional track for educators and providers. Something accessible for the public so we could send people in our classes to the website.

Educate more on preconception care. Get healthy NOW, not just when you are pregnant. Eat healthy, exercise. Show children by doing it. Become healthier as a whole.

# Another category of common messages related to pregnancy and parenting:

- Be healthy. If you have a healthy body, you will have a healthy baby.
- A healthy baby starts with a healthy mom.
- Get early prenatal care.
- ♦ Breastfeed.
- ♦ Keep your baby safe.
- Get help for depression.
- ♦ Be involved as a father.

# Again, opinions differed as to the most important audience(s) for these messages:

African-American women...If you have had or are going to have a baby, take care of your body and get prenatal care. Be healthy before, during, and after pregnancy so you can breastfeed.

We can't just focus on minority populations. When a woman has her first child, despite income and education, a new mom has anxiety and questions.

Interconception women because that's where the biggest volume is. Even though you've had a baby and the experience was a certain way, go to prenatal class to learn about your options.

A few participants stated that providers need more education about high-risk pregnancy conditions and postpartum depression.

Know the warning signs and what to do. There are interventions for treatment of previous preeclampsia or women who are at risk ... treatment to prevent preterm birth...cardiac disease is becoming the number one cause of maternal death. Learn the clinical signs to prompt the next level of evaluation.

Arm doctors and family members with knowledge about the signs of postpartum depression and how to encourage women to be screened.

A few stakeholders noted the complexity of the issues, stressing that getting the right messages to the right populations will not magically solve the problem.

It's more of a culture change, not quick. We need people to take care of themselves. That's the most important. It's boring, but to change the culture give attention to the 12-year-old boy or girl who is overweight. Or depression in young people.

The message is to manage your health conditions prior to pregnancy. That's an unfair message because low-income women don't have access to care. There are some chronic disease management things you can do without a doctor, for example, nutrition, exercise, maybe smoking cessation, but that may not be enough.

Finally, stakeholders and coalitions members said that a campaign should include information for women about what to do if they do not have insurance, where to get contraception, and who to call with a question or problem (noting that 2-1-1 is too general and the people who answer the phone are not navigators). A campaign would be useful for healthcare providers if it included a life planning tool, links to webinars, and information about conferences and local resources.

Beyond the content of the campaign, coalition members and stakeholders offered ideas for its look and feel:

- ♦ Make the campaign very visual. Use images of happy, healthy women, children, and men. Use eye-catching images that reflect the intended audiences.
- Use short videos to allow women share their stories.
- ♦ Make the campaign inviting and nonjudgmental.

An appealing 3 minute video for women, for example, the warning signs to pay attention to, general things to pay attention to. If you have any of those things, speak up. Print goes in the trash.

Women love, love, love quizzes, like on Facebook. Create a risk assessment quiz. Do something like Text for Babes. Make connection easy and ongoing. An iPad quiz where there is feedback, discussion, interactive so women get something back.

Several participants stressed the need to make the campaign relevant to multiple audiences, but there was no consensus about who those audiences should be. Examples included:

- Address different life stages for women and men.
- Resonate with women of all ages, in different communities, not just serve as a reflection of urban areas.

◆ Be relevant for teens under 18, women who have not had a baby, African-Americans, Hispanics, and men.

Other ideas on how DSHS could increase the relevance of a state campaign included:

- ♦ Focus on women, not mothers.
- Make the campaign customizable so communities can modify it with their local spin.
- Help the coalitions find a way to measure the local impact of a campaign.
- ◆ Help coalitions learn how to drive people to a new website that would be part of the state's campaign.

Participants also suggested a wide range of communication channels for DSHS to consider. The most commonly recommended channels were social media and smartphone-friendly resources, such as interactive apps for women and families, and podcasts to educate providers. Other ideas included:

- Ads for busses and bus stations
- Channels specific to the African-American community
  - Community newspapers
  - Barbershops and beauty salons
  - Historically black colleges and universities
  - National sororities, fraternities, and service organizations
- Public service announcements for radio and TV
- ♦ Billboards
- ♦ Print
- ♦ Provider associations
- ♦ Local and state-level fatherhood organizations

Half of the coalition members had never heard of the DSHS Someday Starts Now campaign or used any of its resources. Of those who were familiar with it, several praised its reproductive life planning tool and two participants said they had used the beauty and barbershop toolkit. Representatives from two communities said they had relied heavily on the campaign, basing local campaigns and materials on it. One clinical provider loved the campaign, but learned it did not resonate with the preconception audience.

Suggestions for making the next campaign more helpful included offering a tool for birth planning as well as making it friendlier for males, more relevant for adolescents and women who are not mothers (preconception), and more appealing to Hispanic and African American populations. Other ideas for improvements included giving local communities tools to help drive people to the state's new website and teaching communities how to measure the local impact of a statewide campaign.

#### **Ideal Statewide Network**

Researchers then asked all interview participants to envision an ideal statewide network of people and organizations working together to improve health for women and children. Different pictures emerged from the coalition members and the stakeholders; the findings are reported separately below.

#### **Coalition Members**

Coalition members described two aspects of a statewide network: structure and resources. In terms of structure, they envision the local coalitions connected through technology, meetings, and conference calls:

- ◆ A central online hub to share what is working and not working. Many participants were not familiar with Basecamp, the platform currently used by DSHS to provide information to coalitions. Some participants who have used it say it is not user friendly, and they find it hard to remember to check it.
- ♦ Statewide and regional meetings held regularly (e.g., once or twice a year), which could include conferences, peer learning groups, or informal meetings to share information, discuss issues, and solve problems that arise.
- Regular conference calls or online meetings, maybe quarterly.

According to interview participants, the most valuable resources DSHS can provide to the coalitions include:

- Information about what other coalitions are doing
- Resources and interventions that work
- ♦ FAQs
- Technical assistance and training, in-person or online on:
  - How to build a coalition
  - Collecting and understanding data and statistics
  - Strategic planning
  - Value of systems change efforts vs. programs
  - Unconscious bias
  - Social determinants of health

 Details about the Texas Women's Health Program so coalition members can promote the program and help women enroll

Two participants were particularly clear about resources they believe would help their communities succeed:

We are having to go out and find training ourselves, which is costing the grant money. It should be brought to us. Teach us where to go for data. We have epidemiologists on our coalition and vital stats, but we don't know how to use them. We don't know what to ask for, so they don't know what to give me. I don't speak their language to help them understand what I need.

Coalitions that have been successful can train others to be successful. Workshops to help get the program off the ground. It's hard to know where to start... Someone to guide you, but you still can make it your own.

## **Stakeholders**

Stakeholders identified four aspects of an ideal statewide network: partners, structure/alignment, connections, and resources. They envisioned a diverse group of people and organizations working together as partners:

- Women and men who represent diverse populations
- Non-governmental, community-based organizations, including non-traditional advocacy organizations such as Positive Birth Network and Black Mommas Matter
- Churches
- Businesses
- Medical and nursing schools
- Healthcare providers, including hospitals, primary care providers, and nurses
- State and local government agencies
- Insurance providers

Several stakeholders mentioned how hard it is to keep up with so many organizations working on women's health without a central coordinating body. Two participants envisioned a structure with all parties aligned within it to make the work easier, with the Texas Collaborative for Healthy Mothers and Babies as the organizing body.

We have it already: the Texas Collaborative for Healthy Mothers and Babies (TCHMB). There are too many cooks in the kitchen. DSHS, TCHMB, regional advisory councils, A&M, March of Dimes (MOD). It is really confusing. Each has their own thing. Pull everyone back and do it as one big group so everyone uses the same messages, rather than different messages. One unified group of people.

The Maternal Morbidity and Mortality Task Force (3MTF) is doing research on maternal morbidity and mortality. Morbidity represents a measure of women's health. That research leads to recommendations that would be fleshed out and actualized by the TCHMB. The collaborative should be an umbrella/clearinghouse. They should not be doing research. They should be the body that coordinates all the spokes, like the MOD, Texas Medical Association, giving direction toward implementing the recommendations from the 3MTF and Perinatal Advisory Council.

Another participant highlighted the challenges when organizations working toward similar goals are not aligned, something that a more coordinate effort can address:

It's easier for me to do my job if I have a network. I'll give you the info, and you send it out ... But you have to say, "We all agree to the same thing." Sometimes things don't work because there is no buy-in, for example, for STDs, I may want to do free testing and give away free condoms, but someone else says, "No, that encourages sex." If all are not bought into the same plan, then that's an issue.

Several stakeholders echoed the coalition members' call for a user-friendly central online hub for connecting members and sharing information.

The perinatal collaborative has a site for clinical information. I'm not sure if people are aware it exists. Set up something like that with different information and make providers aware of the website. There are too many places to go for information. Finding things on the DSHS and HHSC websites is challenging.

If we had a database, not for patient info, where at a glance we could see different programs and requirements.

One stakeholder underscored the need for making it easier for healthcare providers to find information:

So much of the info about maternal and child health, you only know about it if you are on X committee, part of a secret society. 80% of women on Medicaid in Harris County get care from physicians in private practice. We have to let them into the secret society.

Stakeholders' ideas for useful resources DSHS could provide mirrored some of the coalition members' ideas. For example, stakeholders suggested that DSHS sponsor

conferences and establish in-person and virtual workgroups. Specific to clinicians, one stakeholder recommended that DSHS work toward requiring continuing medical education (CMEs) on topics considered critical learning, or attach training requirements to hospital licensure. Another idea for getting information to healthcare providers involved electronic medical records (EMRs).

The best way to get info to providers is electronically. Incorporate available resources into EMRs so it would be instantaneous. Pop-ups. X patient lives in this area and there are prenatal classes in her neighborhood.

### Conclusion

The coalition members and other key stakeholders across the state who participated in interviews clearly identified their progress and needs locally and statewide. They also offered insights to improve their network as well as for an engaging and effective statewide campaign related to maternal and child health. Their specific recommendations can be found in the Recommendations section at the start of the report.

# **National Campaign Review**

### Introduction

There are a wide variety of existing public health campaigns and initiatives targeting the *Healthy Texas Mothers Babies* key audiences with aspects of women's health, preconception health, interconception health, and infant health messages. The campaigns and efforts included in this review are at the national, state, and local levels – including both existing social marketing campaigns as well as longstanding and highly successful public health campaigns on other women's health topics (such as *Go Red for Women* and *Susan G. Komen*) reaching similar target audiences.

They feature diverse approaches that can support, complement, and inspire work in Texas to achieve both a multifaceted statewide campaign and customizable options and messages that can be implemented locally. Each features multiple strategies to engage audiences with an emphasis on electronic resources, social media, and peer-to-peer support options as well as expert guidance. The majority take a social marketing approach (i.e., an audience-informed approach to behavior change that combines elements of social science research and commercial marketing). While full evaluation information is not always available for all campaigns, especially those that are ongoing, all have impressive reach and interesting components to consider.

# National and State Campaigns

#### **Show Your Love**

#### Information:

http://showyourlovetoday.com/

**Location**: Nationwide, with online information/resources/outreach

## **Description/Components:**

Show Your Love (SYL) is a



national preconception health campaign originally launched in 2013 and designed "to promote wellbeing and support young adults as they strive to achieve their goals and make healthy lifestyle choices." SYL has sparked a national conversation and was created and implemented by a public-private partnership of more than 70 organizations, The National Preconception Health and Health Care Initiative (PCHHC) and is an initiative of the University of North Carolina School of Medicine Center for Maternal and Infant Health (see: https://www.mombaby.org). The current iteration launched in June 2016 and states that it is the "first and only national, consumerfocused preconception health educational and community-building platform" in the country. The website and materials provide easy-to-digest information and resources related to preventative well visits and other preconception health topics to include eating well, daily vitamin supplementation, exercise, learning about your medical history and more. They are currently being updated and revamped as well.

SYL engages young women and men through an array of online resources on the website, the Preconception Peer Educator Ambassador Program, open-access webinar series, and newsletters.

#### Social Media:

SYL also has social media channels (Facebook, Twitter, Instagram), and innovative social media strategies like audience-driven community building, and custom social media questionnaires. Outreach on Twitter includes periodic, focused Tweet chat sessions on key health topics. (The image below highlights a bilingual example.)



SYL had a sub-grant program to engage activate local community partners in their local messaging and implementation. They awarded 14 mini grants of up to \$5000 each to organizations across the country who continue to act as key partners and ambassadors. The subgrantees each implemented strategies to engage specific underserved populations and communities (e.g., young African American women; middle aged Latinx women; young Pacific Islander women and men; rural, low income populations; LGBTQIA young adults). Engagement strategies were diverse – from focus groups (digital and in person) to advertisements to photo shoots to community events to a coloring book contest to a texting campaign.



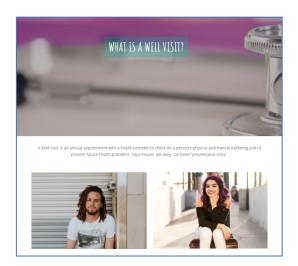


Through PCHHC, SYL also engages clinicians and professionals through a learning collaborative that includes grand rounds presentations and webinars, peer-reviewed publications, the 2017 re-launch of the Before, Between, and Beyond Pregnancy initiative and website (https://beforeandbeyond.org) that includes resources and 6 free continuing education modules and targeted social media channels (LinkedIn and Twitter).

SYL has also reached a general audience, including the above groups, through an array of news articles, presentations, and a newsletter.









## **Outcomes/Evaluations:**

During 2016-2017, SYL estimated that its preconception health-related messages made more than 1.1 billion impressions on young adults,

clinicians, and community members. Since January 2016, there have been 581 unique website visitors per month and PCHHC has become a go-to source for news media. Learning collaborative presentations have reached over 200 healthcare providers and 50 administrators in 14 locations; PCHHC has reached over 8,000 healthcare, public health, and social work professionals via conference and webinar presentations while peer-reviewed and news articles are reaching considerably more professionals and community members and some metrics are difficult to fully track accurately. The campaign and its consumer-friendly social media engagement strategies have become a model for other partner and public health campaigns.

2016-17 Media Metrics	
Traditional Media:	Impressions
Press release 1 - PPC Measures	442,383,995
Press release 2 - SYL Launch	85,559,784
Organic Media Placements	580,963,300
Social Media Reach:	
PCHHC/SYL Twitter	281,000
SYL Facebook (12K	144,000
impressions/mo.)	
Site Properties:	
Before & Beyond Website	30,000
Impressions	30,000
SYL Website impressions	20,000
Newsletter (av. 400+ opens/27	10,800
letters)	
TOTAL:	1,109,392,879

The 2016-17 Media Metrics comes from the *The National Preconception Health & Health Care Initiative: W.K. Kellogg Foundation Evaluation Report – April 2017.* 

### Power to Decide

**Information:** <a href="https://powertodecide.org/">https://powertodecide.org/</a>

**Location**: Nationwide, with online information/resources/outreach



**Description/Components**: Formerly known as *The National Campaign to Prevent Teen* and *Unplanned Pregnancy, Power to Decide* is a leader in the work to prevent unplanned and teen pregnancy with a focus on support and solutions for young people who are economically disadvantaged or marginalized, the campaign also works to address and dismantle the myriad of factors contributing to teen and unplanned pregnancies.

### The Power to Decide initiative includes:

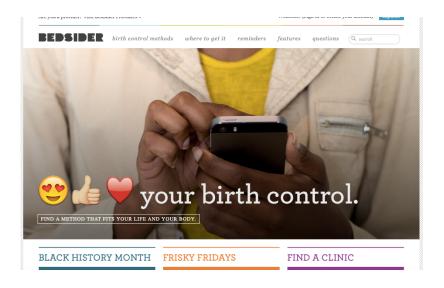
- Evidence-based information, data, and a resource library for a variety of audiences, including young men and women, parents and mentors, service providers and other professionals, policymakers, and the general public.
- Policy advocacy to fight for equitable access to birth control and health information across the country.
- Targeted campaigns, curricula, and work with the media, healthcare providers, and key stakeholder to integrate specific health messages.
- Opportunities for young people to become informed on sexual and reproductive health and advocate for themselves.
- Training and technical assistance consulting to programs, providers, and stakeholders.



Power to Decide has multiple targeted and separately branded initiatives, including:

**Bedsider**, an online birth control support network with evidence-based resources and training. Bedsider is a comprehensive program and campaign with its own website, brand and resources. (More information: <a href="https://www.bedsider.org">https://www.bedsider.org</a>)

**One Key Question**,® a curricula for healthcare providers centering on the question: "Do you want to get pregnant in the next year?" and specific follow up direction and resources based on the patient's response.



The website includes a wide variety of resources and information, including data maps, English and Spanish educational resources for purchase (e.g., postcards, brochures, posters, and more for both professionals and mentors), and materials for teens/young adults (e.g., apparel, cell phone cases, koozies, lip balm, and more).

# Social Media and Support for Local Innovation:

*Power to Decide* also engages target audiences through newsletters and social media channels (Facebook, Twitter, Instagram, YouTube) with ready-made sexual and reproductive health-themed posts.





It also has a new program called **Innovation Next**, which aims to change sex education for the 21<sup>st</sup> century through a unique accelerator program focused on funding and supporting technology-based innovative ideas and projects to address adolescent sexual health and prevent teen pregnancy. Local innovation teams submit research and evidence-based project proposals, and receive development, prototyping, and implementation support. (More information is available here: <a href="https://innovationnext.org">https://innovationnext.org</a>)



**Outcomes/Evaluations:** The *Power to Decide* 2015 Annual Report indicates more than 12 million visitors to the website and 250,000 subscribers to electronic newsletters and social media channels. It also reports that women who used Bedsider were nearly four times less likely to report an unplanned pregnancy than their peers.

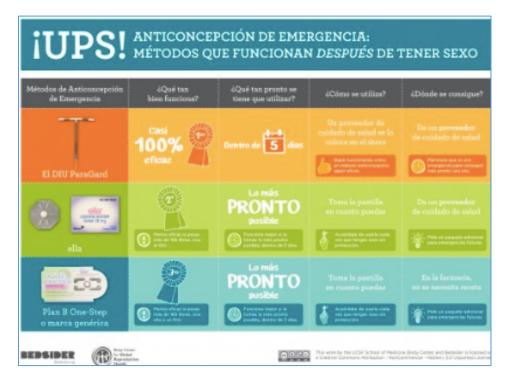
One Key Question was implemented in a variety of locations and is part of a randomized control study. Initial results in 6 healthcare sites indicate the feasibility of integrating this program into a variety of sites as well



as its potentially positive results on reproductive health care. More information is available here: https://powertodecide.org/system/files/resources/primarydownload/Summary-of-Research-on-One-Key-Question\_0.pdf

The implementation of Innovation Next is currently being evaluated using a developmental evaluation approach and features qualitative research with participants (innovation teams).

Overall, *Power to Decide Since* notes that, since peaking in the early 1990s, the teen birth rate has fallen 70% overall and 7% in the last year alone. While there are many factors that contribute to this trend, their work has an influence nationwide.



## Go Before You Show

**Information**: <a href="http://www.gobeforeyoushow.org/">http://www.gobeforeyoushow.org/</a>

**Location**: Nationwide with state, local, and regional licensed partners

**Description/Components**: Go Before You Show is a trademarked campaign of the Fernandes Group with the goal of creating a public education effort to encourage women to seek prenatal care within the first 3 months of pregnancy. It mainly targets women who are already pregnant and is specifically designed for use in communities with elevated rates of pregnancy, pre-term birth, pregnant women not receiving prenatal care, elective induction, and cesarean sections before 39 weeks gestation.



Pregnant, or think you might be?



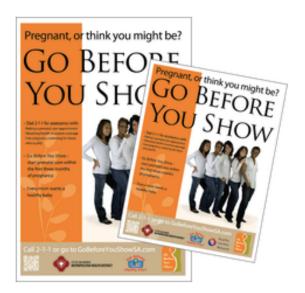
Becoming a licensed partner for Go Before You Show® can be a very cost-effective way to create a campaign for pregnant women on a local, regional and statewide level. We have materials available in English and Spanish. Translation services are also available upon request.

The campaign provides branded materials that simply convey information related to maternal health-related resources, steps to take when pregnant, health insurance and alternatives, and transportation to appointments. The following materials are available in English and Spanish: a website template, radio and television spots, flyers, posters, brochures, billboards, transit boards, banners, digital banners for internet and more.

Go Before You Show partners with local, regional, and statewide entities (e.g., cities, local health initiatives, and nonprofits like the March of Dimes) to create customized campaigns as well as amplify its message and reach. Corpus Christi, San Antonio, Houston and the Brazos Valley all have this campaign as part of public health efforts.



**Outcomes/Evaluation**: None provided/no response to requests. The San Antonio *Go Before You Show* campaign has no current evaluation metrics available as they do not have current funding to capture this information.





# **Every Woman California**

**Information**: http://www.everywomancalifornia.org/

**Location**: California, with online information/resources/outreach



**Description/Components**: Every Woman California is the official platform of the Preconception Health Council of California that features preconception health information presented on separate pages for women, teens, men, peer educators, and health professionals. It includes educational information and resources for each

To join text LAFAMILIA to 55000°

FREE text messages to help improve your health!

audience as well as for providers to use with patients.

There is also a Spanish site.

The FAMILIA Text Messaging Program provides participants with tips on family planning, nutrition and maintaining a healthy weight, reducing stress and more via free text messages in English or Spanish for three months. Each message links to the FAMILIA website for additional information and related apps, blogs and videos. Every Woman California also engages target audiences on Facebook and Twitter channels.

**Outcomes/Evaluations**: Current evaluation information and metrics are not available. The campaign reported that it is between funding and is not currently tracking these data.

# **Every Woman North Carolina**

**Information:** <a href="https://everywomannc.org">https://everywomannc.org</a>

Location: North Carolina, with online

information/resources



**Description/Components:** Every Woman North Carolina is part of the March of Dimes North Carolina Preconception Health Campaign (formerly the award-winning North Carolina Folic Acid Campaign), a statewide initiative that aims to reduce infant mortality, birth defects, premature birth, and chronic health conditions in women, while also aiming to increase intended pregnancies in North Carolina. Its target audience is women and those that influence them – partners, healthcare providers – who are not yet pregnant.

The campaign features a variety of free resources – both online lists and articles as well as brochures, posters, and more available to order or download. Some are available in Spanish. There are also 2 educational curricula (one for middle school students, one for teens), targeted outreach programs (e.g., for young families, new parents, and for vitamin distribution), and a peer health Latina Sana promotora program. Every Woman North Carolina also maintains active social media channels (Facebook with over 4,200 followers, Twitter with over 700 followers, YouTube, and Pinterest) and offers a free continuing education webinar series and guidance for healthcare providers on using its resources.

Outcomes/Evaluations: Metrics from 2017-2018 are available in the graphic here. No additional evaluation information was provided/no response to requests.



### PowerMeA2Z

#### Information:

https://www.powermea2z.org/

Location: Arizona, with online

information/resources



**Description/Components**: PowerMeA2Z is an award-winning Arizona Department of Health Services (ADHS) campaign created by SUMA Social Marketing that began in 2013 as a folic acid distribution initiative aimed at reducing neural tube defects by increasing folic acid vitamin consumption among all Arizona women ages 18-45 years regardless of their pregnancy plans as well as raising awareness about preconception and interconception health topics. Through the campaign messaging, website, advertising, and grassroots partnerships, women receive multivitamins with folic acid and relevant, straightforward, and motivational health information. Content is organized into the following website menu

choices: Know, Feel, Do, Avoid, Plan with vitamin information featured prominently on the home page. The campaign has an emphasis on social media (blogs, Google AdWords and

Facebook Ads).

PowerMeA2Z was designated a Promising Practice by the Association of Maternal & Child Health Programs (AMCHP) in 2016.

PowerMeA2Z was expanded in 2017 to ensure its reach to every county in the state through



expanded grassroots partnerships, purchased media, and social media advertising. This includes outreach to healthcare providers to teach them about the campaign and availability of free vitamins as well as a sustainable network of community partners including OB/GYNs, WIC, nursing schools, associations, universities, promotoras, the Pharmacy Association, and more. SUMA created the first partnership between ADHS and the Pharmacy Association.







Outcomes/Evaluation: 180,000 free 90-day supplies of vitamins with folic acid have been distributed to AZ women between February 2013 and June 2018. *PowerMeA2Z* was evaluated an electronic survey of 500 women as well as metrics on website traffic, community partnerships, and vitamin (PowerPack) distribution. Of the vitamins the campaign distributed, about 36% of those through the campaign's educational website (with 197,000+ unique users), and



about 64% through a network of over 250 outreach partners and outreach to 450+ OBGYNs. Evaluation data indicate that, 74% of women surveyed who have interacted with *PowerMeA2Z* made at least one health behavior change as a result.

# Smart gals know: take your vitamins everyday!

# Why YOU Should Take a Multivitamin

The foods listed in the Vitamin Chart are excellent sources of nutrition, but you would need to eat lots of them to get what you need to power your health. That's why, in addition to eating fruits, vegetables, and whole grains, a single multivitamin with 400 mcg of folic acid (B9) is a great and easy way to make sure you get your recommended daily allowance (RDA) of vitamins!



Take the quiz and order your free vitamins.

# Power Your Life, Power Your Health

**Information:** http://poweryourlife.org/

**Location:** Utah, with online information/resources

Description/Components: Power Your Life, Power Your Health, is award-winning and comprehensive public health campaign of Utah's Maternal and Infant Health Program created by SUMA Social Marketing and launched in 2009. It targets young women and their partners with educational and motivational messaging through a variety of media sources and grassroots efforts. With a focus on minority and low-income populations, the campaign website highlights and is organized around what women need to plan, know, feel, do, and avoid in order to maintain a healthy lifestyle. Although not solely dedicated to preconception or interconception health, the website contains birth control as well as pregnancy planning and spacing information. It also features interactive components like an informative quiz to test health IQ. The campaign reaches its target audience through social media channels (Facebook, Twitter, Pinterest) and hosted a continuing educational event with nationally recognized experts for providers.



**Outcomes/Evaluation:** Within the first 2 years of the campaign, outcomes included substantial website traffic and a 13% increase in the awareness of the importance of folic acid from pre-test to post-test phone surveys. The campaign also had a direct positive impact on target audience attitudes: respondents aware of the campaign were 3 times more likely to consider "taking folic acid" an important health behavior. Respondents aware of the campaign were 7 times more likely to be taking a daily vitamin with folic acid. There was also a significant increase in folic acid intake among special targets,

including young respondents (+20%), non-white respondents (+35%), and pregnant respondents (+61%). The Maternal and Infant Health Program is currently making updates to the campaign website to ensure its ongoing relevance and engagement, including opportunities presented by well woman visits.



# **Delaware Thrives/DE Thrives**

**Information**: <a href="http://dethrives.com/">http://dethrives.com/</a>

**Location**: Delaware, with online information/resources

**Description/Components**: *Delaware Thrives (DE Thrives)* is a project of the Delaware Division of Public Health, the Delaware Healthy Mother and Infant Consortium, and partner organizations with the goal of supporting healthy mothers, babies, families, and communities with educational resources and programs such as home visiting, peer education, health ambassadors, support groups, educational resources, webinars, a health champion award program, and more. It targets a wide audience – women, men,

DELAWARE MOMS ARE **HEALTHY MOMS** 





teens, families, the larger community, and home visiting and safe sleep providers. It also includes an array of health topics (e.g., safe sleep, dental care, parenting children with special healthcare needs, developmental screenings, life and reproductive health planning, health equity, and more).



## **Outcomes/Evaluation:**

During 2018, the campaign website reports the following metrics:

- 25,382 users visited campaign web pages
- ♦ 58,238 pageviews
- ◆ 34,773 sessions (a group consecutive interactions by one user)
- ◆ 3,397 of these were returning visitors and 24,935 were new visitors



- The majority of these users were from Delaware
- ◆ The majority of the users on the site range from 25–34 years old (33% of all users). Out of all users, 60% are female and 40% are male.
- User reach the website as follows: 43.4% through an organic search, 35.7% go to it directly; 8.4% through social media; remaining visitors reach it through paid searches or referrals from other sites. Top search terms included versions of the campaign name, "free condoms," and preconception health terms
- The top pages visited on the site included:
- ♦ Home visiting programs/providers
- Order materials
- ♦ Home page
- ♦ My Life My Plan (women)
- ♦ Programs page
- Help Me Grow (information on a multi-partner pregnancy and child development support program)
- ♦ Blog "Soft or Firm Mattress for Babies?"
- Safe sleep
- Contact (to reach the campaign)

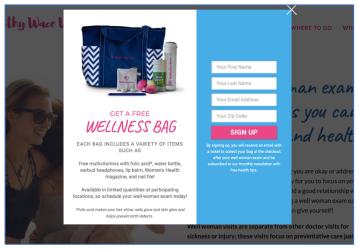
# **Healthy Waco Women**

This campaign is included in this review as an example of what a local community can do to extend and complement other campaigns, efforts, and resources.

**Information**: <a href="https://healthywacowomen.org/">https://healthywacowomen.org/</a>

**Location**: Waco, TX

Description/Components: This targeted preconception public health campaign focuses on the importance of annual well woman exams and preventative care. In addition to providing basic information about what questions woman may want to ask and what to expect during the exam (with an embedded video which gives and overview of the exam), the website



lists and maps the location of local providers offering free or low-cost services. A pop up window also offers visitors a free wellness bag with Folic Acid multivitamins, lip balm, a water bottle, and a health magazine. Featuring only three main web pages, the site is easy to navigate and employs simple language and messaging to reach woman of all ages and from diverse backgrounds with a simple message.

**Outcomes/Evaluation:** The site was launched January 2019; no evaluation information is available yet.



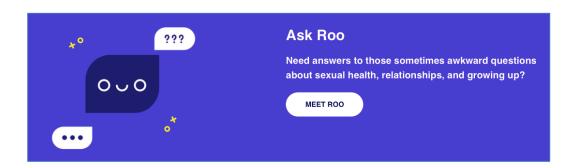
# **Social Media Creative Approaches**

Social media is a proven way to reach younger audiences, including women and men in the preconception and interconception periods. The following social media and related creative approaches are included in this review as examples of the range of what is possible using social media. (Also see the social media sections in the other campaigns reviewed earlier in this report, especially *Show Your Love* and *Power to Decide*.)

# Roo, Planned Parenthood

**Information**: <a href="https://roo.plannedparenthood.org/onboarding/intro">https://roo.plannedparenthood.org/onboarding/intro</a>

Planned Parenthood recently launched Roo, a new sexual health chatbot that instantly connects young people to the care and information they need – 24 hours a day, seven days a week. Roo is part of Planned Parenthood's ongoing commitment to utilize technology and innovation to meet people where they are, and to provide information however and whenever they need it.



# #IDEFY, Planned Parenthood

**Information**: <a href="https://www.plannedparenthood.org/about-us/newsroom/press-releases/planned-parenthood-announces-idefy-campaign-to-ensure-young-activist-future">https://www.plannedparenthood.org/about-us/newsroom/press-releases/planned-parenthood-announces-idefy-campaign-to-ensure-young-activist-future</a>



Launched in 2017, this social media campaign that inspired young people to use social media to share with the world what they defy – racism, homophobia, slut-shaming and beyond.

They were asked to participate by posting an image of themselves on social media with the word DEFY written on their fist and a caption using the hashtag #IDEFY.

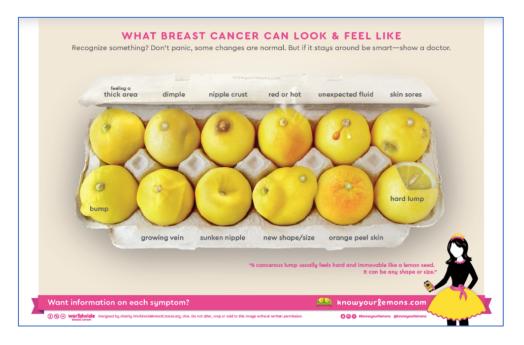
This campaign launched with a Facebook Live event at the same time that other related activations were taking place around the country (e.g., the 44th anniversary of Roe v. Wade and one day after the Women's March).

A number of social media campaigns that rely on a hashtag and encourage posting of a specific image have had success with younger audience.

# #KnowYourLemons, Worldwide Breast Cancer

**Information:** https://knowyourlemons.com/symptoms

This campaign centers on an easily shared image illustrating the twelve signs of breast cancer. The image is of 12 lemons sitting in an egg carton and it spread quickly over social media. The campaign taught women and men to easily recognize the 12 most common breast cancer symptoms. It was also designed to break the taboo and fear of this disease using a friendly and approachable visual to explain breast cancer. The image provides a great deal of information efficiently and avoids unpleasant graphics/photos.



# One Bad Mother

**Information**: <a href="https://www.onebadmotherpodcast.com">https://www.onebadmotherpodcast.com</a>

One Bad Mother is being included in this campaign review as an example of a creative social media approach and alternative strategy that presents an opportunity to reach and engage key audiences in an ongoing way.

This is a comedy podcast about parenting that features peer-to-peer engagement, a highly supportive, collaborative approach, and the insights of a diverse array of expert guests. The related Facebook group has over 10,000 followers and is closely moderated by select parents and the show's hosts (also parents). There are also a number of subgroups on select topics (e.g., breastfeeding) or for parents in certain cities/areas. The majority of the audience is mothers (and fathers) of babies or young children.



# SpeakBeautiful, Dove

**Information**: https://www.dove.com/us/en/stories/campaigns/speakbeautiful.html

By partnering with Twitter, Dove was able to highlight the fact that 80% of women's body negative Tweets are about themselves – and then launched a campaign focused on

building self-esteem among women,

especially young women.

# #speak**beautiful** Dove

# **#MOMLISTS**

Information: http://minnadubin.com

The project started in 2015 and has over 700 followers on Instagram. #MOMLISTS is included in this review as another example of an innovative social media engagement strategy that could include public health information. This is a San Francisco-based art project that targets and engages mothers and parents locally and on social media nationwide about parenting struggles and topics. The creator, Minna Dubin, posts "mom lists" around the city as well as on social media (Instagram, Tumblr, Facebook, Twitter) written by guest contributors about topics as diverse as self-care, developmental assessments, everyday struggles with a baby, and much more.



# Additional Considerations for Social Media

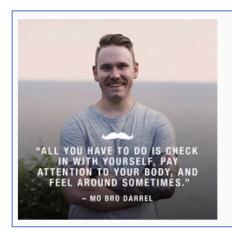
While not focused specifically on reproductive health audiences, the following are additional examples of social media health campaigns have been successful in broad audience engagement:

*Ice Bucket Challenge, ALS Association* – raised awareness through word-of-mouth marketing by encouraging audiences to post image of pouring ice buckets on themselves, then challenging someone else on social media to do the same.

17 million videos uploaded; 400 million people viewed videos

Tied to clear health gains, see: <a href="http://www.alsa.org/fight-als/ice-bucket-challenge.html">http://www.alsa.org/fight-als/ice-bucket-challenge.html</a>

- ◆ #Movember, Movember Foundation raised awareness, funding, and reduced stigma around men's health issues (e.g., prostate cancer, testicular cancer, mental health, and suicide prevention) through an annual social media campaign encouraging men to grow their mustaches every November. This campaign leverages organic conversations, "Why are you growing your mustache?" to spread its reach and impact.
- ♦ #HereForYou, Instagram increased support for those with mental health challenges by both raising awareness and reducing stigma using a targeted hash tag attached to audience stories related to their own mental health. This campaign was launched by Instagram and, while it did not have initial ties to social services/support organizations, it creates the opportunity and momentum for these partnerships.







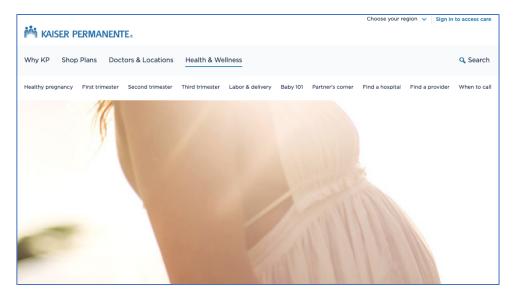
# Commercial Health Resources

Major insurance companies offer targeted information and resources to women and families about maternal health, prenatal care, and infant care that touch on key preconception health and healthy woman/baby topics. Outreach is limited to those insured by each company and it is unclear of the reach, use, or impact of the following resources though there is potential to engage networks of women nationwide. This section is included to provide examples of insurance company efforts that can inform and complement public health campaigns.

#### **Kaiser Permanente**

**Pregnancy and More**: <a href="https://healthy.kaiserpermanente.org/health-wellness/maternity">https://healthy.kaiserpermanente.org/health-wellness/maternity</a>

This website includes a variety of articles for pregnant mothers as well as a "Partner's Corner" and "Baby 101" on infant care. All articles are simply written and include embedded images and videos. There are also simpler websites dedicated to women's health and men's health that include information on screenings, general health, and birth control/pregnancy planning. Throughout the larger website, there is a variety of topic-specific information on other health and wellness topics, screening information, and more. Most resources exist within the site and are not downloadable.



# **United Healthcare**

# **Healthy Pregnancy Program:**

https://myuhc.phs.com/content/phs/en/phs/maternitysupport.html?orig\_referer=&orig\_page=https://myuhc.phs.com/maternitysupport

# Before Pregnancy, See Your Doctor:

https://www.uhc.com/health-and-wellness/health-topics/pregnancy/before-pregnancy

# Women's Health During Pregnancy:

https://www.uhc.com/health-and-wellness/health-topics/pregnancy

The *Healthy Pregnancy Program* is for pregnant women and they must enroll to receive its benefits. Those include a 24-hour nurse line, targeted educational resources, a cost estimator tool, and a multi-function app that tracks fetal development as well as offers guidance, resources, and tips, and health/wellness tracking for before and after the baby is born.

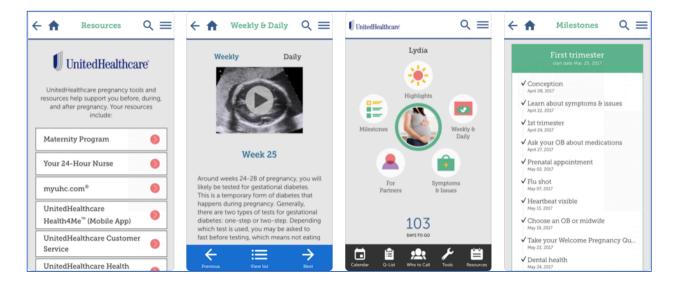
The larger *United Healthcare* program features preconception and pregnancy topics at times too in articles, but it is unclear how these target specific audiences.

# For example,

- ◆ Top Expert Tips: Before, During and After pregnancy (<a href="https://www.uhc.com/newsletters/september-2017/pregnancy-tips">https://www.uhc.com/newsletters/september-2017/pregnancy-tips</a>) or
- ◆ "Foods That Make You Fertile: Nutrition Tips for Women and Men" (<a href="https://www.uhc.com/content/dam/uhcdotcom/en/HealthAndWellness/PD">https://www.uhc.com/content/dam/uhcdotcom/en/HealthAndWellness/PD</a> F/FoodsThatMakeYouFertile.pdf).
- Overview of the Healthy Pregnancy App: https://myuhc.phs.com/content/phs/en/healthypregnancyapp.html

# Social Media Example

United Healthcare had a now defunct social media and web "We Dare You" campaign – to engage with their following and raise awareness for important health topics with monthly quizzes, dares, and photo sharing competitions. While this campaign did not directly target women or men in the preconception/interconception period, it is a notable creative and successfully example.



# Longstanding Campaigns Targeting Women

The following two successful and longstanding public health campaigns target women of all ages and can offer insights and lessons learned for this target population.

# Go Red for Women

**Information:** https://www.goredforwomen.org

**Description/Components**: In 2004, this American Heart Association (AHA) campaign was launched to target women of all backgrounds in raising awareness about the risk of heart disease – that is the #1 killer of women and kills over



500,000 women each year. It is described as a "passionate, emotional, social initiative designed to empower women to take charge of their heart health."

The campaign includes a variety of educational and research-based information, inperson events (e.g., luncheons), media outreach. The core messages of the campaign are to share heart health and risk information, raise awareness of the issue, and encourage women to wear red as a symbol of support. There is a campaign in Spanish as well, *Go* Red Por Tu Corazón, and an online store that sells apparel and raises funds for campaign outreach and heart disease research. The campaign features a number of major corporate and community partners.

**Outcomes/Evaluation**: According to AHA, the campaign a woman who engages with the campaign and "goes red" follows an exercise routine, eats healthier diet, visits her doctor for important tests, and influences others by talking about heart health.

AHA currently reports the following campaign evaluation/impact metrics:

- More than 2 million women have learned their personal risk of developing heart disease by taking the Go Red Heart CheckUp
- ♦ More than 200,000 healthcare provider offices have received campaign materials
- ♦ More than 900,000 women have joined the fight.
- Women involved in Go Red for Women eat a healthy diet
- Go Red women are more likely to follow their doctors' advice from losing weight to taking medications
- 91% of women involved in the campaign visited their doctor in the last 12 months (compared to 73% of all U.S. women)
- ♦ 64% follow a regular exercise routine

- 84% have talked to friends about their heart health.
- 90% have had their blood pressure checked in the last year
- ♦ 75% have had their cholesterol checked in the last year
- ◆ Additional evaluation information: <a href="https://www.goredforwomen.org/en/about-us/milestones">https://www.goredforwomen.org/en/about-us/milestones</a>



# Watch me. Join me. Go Red.

One in three. Heart disease claims the lives of 1 in 3 women. That's a third of mothers, sisters and friends. It's time to be demanding when it comes to women's heart health.

American Heart Association

Join Us.

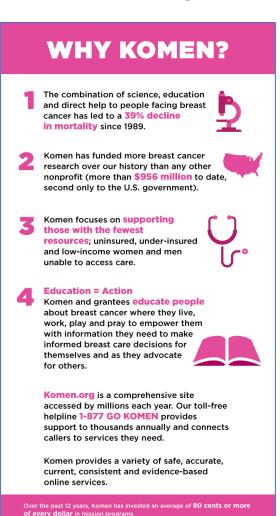
#### Susan G. Komen

**Information**: https://ww5.komen.org

**Description/Components:** Founded in 1982, Susan G. Komen is a foundation dedicated to curing breast cancer that funds research, leads educational



outreach initiatives, and funds screening and treatment worldwide. They combine a social marketing model with fundraising races and medical research in order to address the issue from multiple angles. They have educational information on their website – about screening and prevention, treatment, and survivorship – as well as a hotline and local affiliates that can help an individual who needs resources, answers, or support.



Susan G. Komen engages women with widespread, diverse messaging through inperson events, their website (with interactive elements such as audience video submissions), and a robust social media network (Facebook with 1.9M followers, Twitter with 124k followers, YouTube with 2000+ subscribers, Instagram with 55k followers, Pinterest with 600+ followers, and LinkedIn with 22k followers). They have branded the color pink (and now the slogan "more than pink") as part of their campaign and led a national movement.

**Outcomes/Evaluation:** No metrics on reach are currently available. The organization reports the impacts in this graphic.

# **Additional Models and Projects**

# 4th Trimester Project

**Information**: http://4thtrimester.web.unc.edu/

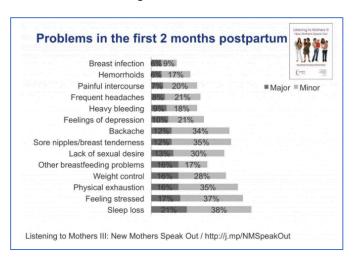
**Location:** North Carolina with national reach

**Description/Components:** As a research project of the University of North Carolina (UNC) Center for Maternal and

Infant Health, UNC School of Medicine and Carolina Global Breastfeeding Institute, the 4th Trimester Project is exploring the postpartum health needs of mothers and babies in order to determine appropriate interventions to impact the most important outcomes. During the "4th Trimester," or the 3 months following delivery, mothers and babies continue to function as a unit and the demands on mothers are extraordinary. The project is bringing together mothers, healthcare providers, and other stakeholders to explore critical health needs, including maternal mood, infant care and feeding, sleep and fatigue and physical recovery from childbirth.

While this is not a social marketing-specific campaign yet, it can offer messaging insights around the 4th trimester concept to be included in a holistic campaign. The project has engaged target audiences of mothers, healthcare providers, researchers, and

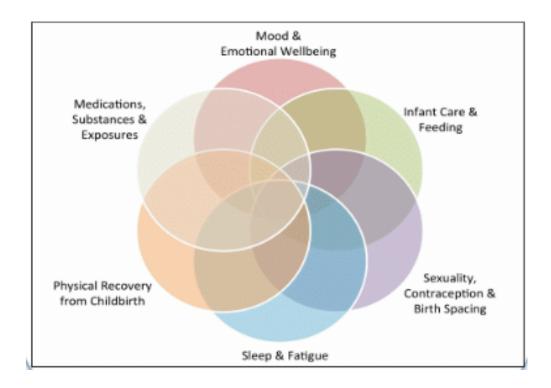
public health leaders via monthly webinars, social media channels (Facebook, Twitter and YouTube), newsletters, face-to-face meetings, and a blog. Investigators' research has been published in the ZERO TO THREE Journal and the American Journal of Obstetrics and Gynecology.



**Outcomes/Evaluation:** Investigators concluded that maternal health needs during the postpartum period intersect and compound one another, demanding more integrated and readily accessible healthcare. It is also clear that additional research is needed to determine how best to meet the needs of mothers and babies during this period. No engagement metrics are available.

An article in the American Journal of Obstetrics and Gynecology (July 2017) is available here: <a href="https://www.ncbi.nlm.nih.gov/pubmed/28390671">https://www.ncbi.nlm.nih.gov/pubmed/28390671</a>

A project summary with initial evaluation information is available at: https://www.dropbox.com/s/15qnam8m5yalktt/4thTrimesterPoster.pdf?dl=0



# Office of Minority Health, Preconception Peer Educator Program

**Information**: https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=9

**Description/Components:** The Preconception Peer Educator (PPE) Program is an innovative model that trains and supports certified peer educators to target other college students with preconception health messages they can spread throughout their campuses and communities. The program's goal is to reduce infant mortality rates among all people, especially those in the African American community who face disproportionately negative birth outcomes. The program was launched in 2007 as part

of A Healthy Baby Begins with You, a program designed to address equity in birth outcomes.

# **Current program snapshot:**

- ◆ State system currently using PPE Program: North Carolina
- States with Maternal and Child Health community organizations collaborating with PPE Programs: New Jersey, Florida
- ◆ These are nonprofit organizations that are maternal and child health focused. They partner with other community organizations, universities, and health departments to promote and improve the health of women, infants and children.
- ♦ Active Programs 2018-2019:28
- Number of students active in program: 437
- Number of states in which there are colleges with PPE Programs: 11

**Evaluation/Outcomes:** This program was evaluated in a 2011 article in the Journal of Communication in Healthcare. The PPE program is currently being revamped, so no current evaluation information is available.



# **Appendix: Focus Group and Interview Guides**

# HTMB Focus Group Guide: Preconception Women, Ages 18-25

# I. Introduction (5 minutes)

Moderator begins by introducing the concept, process, and purpose of the focus group.

- ♦ Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment
- Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements
- Explain why the group was selected to participate and encourage honesty.

**Purpose of group:** The purpose of this group is to discuss information related to the health concerns of women your age.

#### II. Icebreaker

Moderator lays various picture cards around the room and on the table. She asks the group to take a moment to view as many cards as possible and choose the photograph that best illustrates where she is in life right now.

◆ Let's go around the room and share the picture you chose that describes where you are right now in life.

# III. "My Health": Top of Mind, Priorities, and Behaviors (10 minutes)

Moderator lists answer on flip chart as she probes on the following questions.

- ♦ What do you think are the main health concerns for women your age? What are your own health concerns?
- ♦ What do you do to address these concerns?
- What stops you from doing some things you know you should do to address these concerns?
- Who do you talk to about your health concerns? Why
- (*If it hasn't come up yet*) What about reproductive health -like your period, or birth control, who do you talk to?

# **Knowledge and Perceptions of Well-Woman Exam**

- For what reasons have you gone to a doctor or a clinic in the past year or so? *Probe:* flu shot, physical exam, STD test, stress?
- ♦ What, if any health care providers have you talked to about your health. Tell me about those conversations. Were your concerns addressed? (Note to Moderator: many women in this age group do not have insurance so probe to determine what kind of provider health clinic? Private care? Or some may not have gotten care in the past few years − probe for that as well)
- ♦ When I say "well-woman exam," what comes to mind?
- ♦ Who here has had a well-woman exam? (*Moderator takes count aloud for recorder*) What prompted you to go?
- ♦ What happens at a well-woman exam?
- If you haven't had a well-woman exam, what have you heard about them?
- For what reasons do you think some women might not go for the exam? *Probe only if not mentioned:* What are some other barriers—transportation, insurance, don't want a vaginal exam, long wait for an appointment?
- ♦ If you were going to book an appointment tomorrow for a well-woman exam in (*fill in community*), where would you go? Why would you go there—service, past experience, reputation, cost, location? (*Moderator tries to probe each participant*)
- ♦ Have you ever been asked by a health care provider "Would you like to become pregnant in the next year?" or a similar question? If so, how did that make you feel?
- ♦ What would you think if, at your well-woman exam, your provider asked, "Would you like to become pregnant in the next year?"
- ♦ How would that question make you feel? How easy or hard is it for you to talk about birth control and pregnancy planning with a health care provider?
- ♦ Just thinking of everything we've talked about concerning well-woman exams what would make you more likely to go for your next exam or, if you haven't been, go for your first exam?
- ♦ What else would you need to know in order to schedule a well-woman exam appointment? *Probe:* a link to a simple website from Instagram with information about local providers, what happens at the exam, why you need it, a typical Q & A, and cost or insurance information?

#### IV. Social Media

Okay now we are going to switch gears a bit and talk about how you get information.

- What social media are you most likely to use? Facebook, Instagram, Pinterest, Snapchat, others? (Moderator captures the number of users for each of the following by asking participants to raise their hands if they are users.) Probe: What social media platforms do you use the most?
- If you were trying to find out about what is going on socially (for the weekend or an upcoming event), which social media would you use? Or what ways would you find out what is going on?
- ♦ How do you like to listen to music? Local radio stations? Streaming services? Which ones? *Probe:* Do you hear ads when listening on these services or do you pay to have adfree access?
- ♦ What about TV, how do you watch TV cable? Netflix? Hulu? Probe for other
- ◆ Do you use any health-related apps? Which ones? Do you use an app to track your period? (*Moderator takes count aloud for recorder*)
- ♦ Where do you get information about staying healthy? *Probe*: Physical activity, healthy eating, mental health and emotional support? Do you talk to a provider, friends/family, online search, TV shows?

# V. Creative Testing (45 minutes)

The following women's health materials will be handed out one at a time for participants to review. We are now going to review some materials, some print, some TV and radio ads, and a couple of websites. I am going to give you a few minutes for each piece to review them. As you are looking through them, please note what you like or dislike about them, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

# Show 15-second Someday Starts Now TV Advertisement

- ♦ What are your top-of-mind thoughts about this ad? Who do you think this ad is for? Is it for you? If you saw this ad, what would it motive you to do, if anything? *Probe:* What makes you say that?
- ♦ What do you like or dislike about the ad?

#### 30-second Someday Starts Now Radio Advertisement

- What are your top-of-mind thoughts about this ad? Who do you think this ad is for? Is it for you? If you saw this ad, what would it motive you to do, if anything? *Probe*: What makes you say that?
- ♦ What do you like or dislike about the ad?

We are going to switch gears to look at some information that is about your health in general. Give participants time to read through the following materials. Ask them to note anything they find interesting on their note pad.

- Someday Starts Now Life Planning Tool
- Healthy Waco Women booklet
- ❖ PowerMeA2Z booklet
- What did you learn that you didn't know before?
- What, if any, questions come up for you after reading those documents?
- ♦ What do you like or dislike?
- ♦ Which one are you the most likely to read? Why?
- ◆ In what format are you most likely to read this information? Facebook, Pinterest, an App, website—or print?

# La Familia Women's Health Text Campaign

- ♦ What do you think about the idea of signing up for community-specific text messages about women's health? You would sign up and then get simple text messages twice a month with a link to learn more about women's health. Here are a couple examples from another city that has a texting campaign. (Read sample text from the La Familia Campaign as an example.)
  - Text #1: You can get the pill, condoms, the ring, or the IUD for free. Find out how: [link]
  - Text #2: Did you know exercising for 10 minutes twice a day helps you reduce stress? Fun and easy exercise ideas: [link]

What kind of information might you find helpful to receive in these texts?

# Websites (they will spend a few minutes on each site)

◆ First, how do you usually get online – on your phone or on a computer? How many of you have computers? (*Moderator will count hands aloud for the recording*)

Moderator hands out tablets or if participants prefer they can access the sites on their phone.

# Healthy Waco Women Website

Moderator explains how to access the Healthy Waco Women site and ask participants to take a few minutes to explore the site.

- ♦ Based on the first page, whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- ♦ What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

Moderator directs women to 60-second short video on well-woman exams.

- ♦ What are your top of mind thoughts about the video? What did you learn that you didn't know before?
- ♦ How do you feel about getting a well woman exam after seeing the video?

#### PowerMeA2Z Website

Moderator explains how to access the PowerMeA2Z.org site. Moderator asks participants to take a few minutes to explore the site.

- ♦ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- ♦ What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

#### **Show Your Love Website**

Moderator ask participants to access Showyourlovetoday.com

- ◆ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- ♦ What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

#### Bedsider Website

Moderator ask participants to access Bedsider.com

- ♦ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- ♦ What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

Which of the sites based on style and content would you be most likely to go to? What kind of information would you like to see on a website like this?

Are there any other websites about women's health that you have visited in the past? What do you remember about those websites?

What other ideas do you have about making information available to women in your age group? How else would you like to get health information?

Moderator gathers tablets.

# VI. Conclusion (10 minutes)

- OK, we are wrapping up. Just a few more questions.
- In closing, please share on thing you heard tonight that was interesting or that you didn't know before.

Thank you for your time!

# HTMB Focus Group Guide: Interconception Women

# VII. Introduction (5 minutes)

Moderator begins by introducing the concept, process, and purpose of the focus group.

- ♦ Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment
- ♦ Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements
- Explain why the group was selected to participate and encourage honesty

**Purpose of group:** The purpose of this group is to discuss information related to women's health after and between having a baby.

#### VIII. Icebreaker

Moderator ask each participant to introduce themselves and to share the name and ages of their children and to talk a little about themselves such as if they are a student, full time homemaker or have a job outside the home.

Moderator lays various picture cards around the room and on the table.

- ◆ Take a moment to view as many cards as possible, and choose the photograph that best illustrates the biggest health concerns you had about yourself after having your babies? *Moderator stresses "yourself" to keep focus on personal health rather than the babies.*
- ♦ Let's go around the room and share the picture you chose and why.

# IX. "My Health": Top of Mind, Priorities, and Behaviors (10 minutes)

Moderator lists health concerns mentioned in previous exercise on white board and probes to determine what else women are concerned about. Moderator then asks participants to write their top two health concerns from the list on the pad of paper in front of them. Then the moderator conducts exercise to prioritize health concerns.

- ♦ What do you think are the main health concerns for women your age? What are your own health concerns?
- ♦ What do you do to address these concerns?
- Who do you talk to about your health concerns? Why? (Continue to probe until they've talked about all the sources for help including any online resources)

- ♦ Please raise your hand if you went to a postpartum visit. *Moderator counts aloud for the recording*. What happened at your postpartum visit/what did you discuss with the health care provider at that visit? (Probe for talk about birth control, depression/baby blues, vitamins with folic acid, breastfeeding)
- If any, what kind of birth control information did you get at your postpartum visit?
- ◆ Did your provider talk to you about long-acting reversible birth contraception such as IUDs, implants, injections? Examples: IUD = Mirena or Paraguard, arm implant = Nexplanon, injection = Depo Provera. What did the provider say?
- At your postpartum visit, did anyone talk to you about breastfeeding?
- Did the doctor talk with you about diabetes, high blood pressure, depression or other health conditions during your postpartum visit? Did the doctor make any referrals to other healthcare providers at the postpartum visit?
- ♦ What do you wish you had been able to talk about but didn't? How did you feel when you left the appointment?
- ♦ If some women in the group did not go, Moderator will ask them to talk about their reasons for not getting a post-partum check-up.
- ♦ Also, if they did not go to a post-partum visit, if they went to a pediatrician for well-baby visit and if that provider asked mom any of these lines of questions about postpartum care.
- ♦ What do you feel should be more of a concern for health care providers about women's health after they have a baby?
- We talked a little about breastfeeding a minute a go. I am wondering if anyone had a breastfeeding challenge? What did you do? Where did you go? Did you get the information or support you needed?
- What, if any, messages have you heard about breastfeeding and safe sleep for the baby?
- ♦ What else have you heard about safe sleep?

# IV. Knowledge and Behavior - Pregnancy Spacing

- ♦ After you had your first baby how did you decide when to have your next? What were some of the things you thought or considered? Probe: what kind of precautions did you take to prevent another pregnancy right away?
- What, if any, challenges did you face related to sticking to your plan about the next baby?

- ♦ What role did your partner play in the decision?
- What did your provider say about having another baby?
- Many experts recommend that women wait 18 months to 24 months before they get pregnant again. Why do you think that is a recommendation?

# Power Your Family Pamphlet

Moderator will pass out the pamphlet. I am going to give you a few minutes to review this pamphlet. As you are looking through it, please note what you like or dislike about it, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

- ♦ What did you learn that you didn't know before?
- ♦ What did you find relevant to you?
- ♦ What do you like about this piece? What do you dislike?
- How likely would you be to read this brochure if it was given to you by a health care provider?

# V. Knowledge and Behavior - Well Woman Exam

- ♦ When I say "well-woman exam," what comes to mind?
- ♦ Who here has had a well-woman exam? (*Moderator takes count aloud for recorder*) What prompted you to go? Probe: What happens at a well-woman exam?
- ♦ For what reasons do you think some women might not go for the exam? Probe only if not mentioned -What are some other barriers—transportation, insurance, don't want a vaginal exam, long wait for an appointment?
- ♦ If you were going to book an appointment tomorrow for a well-woman exam in (fill in community), where would you go?

#### PowerMeA2Z Website

Moderator explains how to access the PowerMeA2Z.org site. Moderator asks participants to take a few minutes to explore the site.

- ♦ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- ♦ What information was relevant to you?

#### VI. Knowledge and Behavior – Interconception Health

• In recent years, there has been a lot of emphasis on eating healthier foods and getting more physical activity. What ads or messages have you seen that motivate you?

#### Information for Parents of Newborns Pamphlet

Moderator will pass out the pamphlet. I am going to give you about 10 minutes to review this pamphlet. As you are looking through it, please note what you like or dislike about it, and then we will discuss your thoughts. We are looking to brainstorm creative approaches to redesign this piece to make it more relevant to mothers like you. We did not develop these materials, so whatever you say about them will not affect our feelings.

- What do you like about this piece? What do you dislike?
- What would you do to redesign this brochure?
- ◆ This piece has to have a printed component, what changes would you make to the printed version? Probe: plastic tip cards like from the breastfeeding bag? Folder with color-coded pull out cards?
- Would there be another way you would want to receive this information? Online? Phone number?

#### Birth Control After Baby Pamphlet

Moderator will pass out the pamphlet. I am going to give you a few minutes to review this pamphlet. As you are looking through it, please note what you like or dislike about it, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

- ♦ What did you learn that you didn't know before?
- ♦ What did you find relevant to you?
- ♦ What do you like about this piece? What do you dislike?
- How likely would you be to read this brochure if it was given to you by a health care provider?

Moderator gathers tablets.

#### VII. Social Media

Okay now we are going to switch gears a bit and talk about how you get information.

- What social media platform are you most likely to use? Facebook, Instagram, Pinterest, Snapchat, others? (*Moderator captures the number of users for each of the following by asking participants to raise their hands if they are users.*)
- If you were trying to find out about what is going on socially (for the weekend or an upcoming event), which social media would you use? Or what ways would you find out what is going on?
- ♦ How do you like to listen to music? Local radio stations? Streaming services? Which ones? *Probe:* Do you hear ads when listening on these services or do you pay to have adfree access?
- ♦ What about TV, how do you watch TV cable? Netflix? Hulu? Probe for other
- Where do you get information about staying healthy? *Probe*: Physical activity, healthy eating, mental health and emotional support? Do you talk to a provider, friends/family, online search, TV shows?

# VIII. Conclusion (10 minutes)

♦ In closing, please share one thing you heard tonight that was interesting or that you didn't know before.

Thank you for your time!

# **HTMB Focus Group Guide: High Risk Pregnancy Women**

#### I. Introduction

- Moderator begins by introducing the concept, process, and purpose of the focus group.
- Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment
- ♦ Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements
- Purpose of group: The purpose of this group is to discuss information related to women's health after and between having a baby.

#### II. Icebreaker

- ♦ Moderator ask each participant to introduce themselves and to share the name and ages of their children and to talk a little about themselves such as if they are a student, full time homemaker or have a job outside the home.
- *Moderator lays various picture cards around the room and on the table.*
- She asks the group to take a moment to view as many cards as possible, and choose the photograph that best illustrates how you felt about your health during your pregnancy.
- Let's go around the room and share the picture you chose and why.
- ◆ Moderator explains: One thing you all have in common is that each of you had a unique health challenge during your last pregnancy. That may have meant you had a high-risk pregnancy which simply means that you or your baby may have needed extra care during your pregnancy and delivery. Some of the most common reasons your doctor may have identified you as high-risk are having diabetes, high blood pressure, age, and other issues.

Some pregnancies even start out as normal but progress to high-risk based on changes in your body or the baby's during pregnancy. In most instances, high-risk pregnancies simply need additional monitoring to ensure a successful pregnancy and delivery. Our questions today are going to focus on the experiences and care you received during your last pregnancy and right after having your baby (the post-partum period).

# III. "My Health": Top of Mind Concerns

- ♦ Moderator leads participants in a brain storming exercise to list top-of-mind personal health concerns they have about their health after pregnancy. She starts by listing concerns mentioned in previous card sort exercise on white board and probes to determine what else women are concerned about. (Julie/Molly this is similar to what we are doing in interconception group—I want to see if they are the same or if these women know they have complex issues.)
- ♦ Who did you talk to about these concerns? Continue to probe until they've talked about all the sources for help including any online resources. (Do not probe about doctors but listen to see how long it takes for them to come up)

#### IV. Prenatal Care

- ◆ Tell me a little bit about your prenatal care experience, the care you received while you were pregnant.
- ◆ At what point in your pregnancy did you start prenatal care with a health care professional?
- During your prenatal care how did your doctor or nurse address your special health issues? For some that may be Type 2 diabetes, high blood pressure or (moderator draws on medical conditions that were discussed in the early exercises).
- ♦ What kind of prenatal materials or resources did you receive? Were any of the educational materials or resources you received specific to your special medical needs?
- ♦ How comfortable were you about speaking with your provider with questions and concerns about your special health condition?
- ◆ Did anyone here see a health care specialist for a particular medical need or condition? Tell me about that care?
- ♦ What kind of special instructions related to your condition did you receive from your doctor about giving birth and what you could expect to happen at the hospital (your hospital experience)?
- Did anyone take prenatal classes or other health related classes during your pregnancy? Tell me about them. (moderator listen first for anything related to their various conditions to see how it was addressed the probe about that condition)

- ♦ For those of you who did attend prenatal classes, How useful and helpful did you find them? Did they help you to learn more about your pregnancy and what to expect at delivery? For those of you who did not attend any prenatal classes were the classes offered to you? And can you share why you decided not to attend? (probe for barriers)
- ♦ What other things did you do to prepare for childbirth? (e.g. doula, read books, online research)
- ♦ Did you have a birth plan? Why or why not?

#### V. Hospital experience during birth

- ◆ Tell me, how was your birth experience? For your baby? For *you*?
- ♦ What kind of care did you receive related to your special health condition at the delivery hospital? How did you feel about the care you received?
- ♦ What kind of medical instructions did you receive about YOUR health (not the babies) before leaving the hospital?
- What other guidance did you receive about how to stay healthy with your special health condition after leaving the hospital and going home?
- ◆ Did you receive any information about planning for your health condition in the long-term? (e.g. what you need to know about your condition and for any future pregnancies? What you need to know about your condition as you grow older?
- ♦ What kind of community or educational resources did the hospital tell you about? For instance, if you have diabetes did they talk to you about diabetes education classes? Did you seek the resources out? How did that go?

#### VI. Postpartum

- Please raise your hand if you went to a postpartum visit. What happened at your postpartum visit? (probe for talk about birth control, depression, stress, postpartum warning signs, breastfeeding)
- ♦ About how long after baby's birth did you attend this postpartum visit, and how many of these visits did you go to?

- ♦ Was there anyone who did not go for their postpartum visit who is comfortable sharing with us the circumstances that led to you not going?
- What did the doctor or nurse say about the special health condition you had during your pregnancy? Did the doctor's office provide any direction about how to care for yourself during the time right after the baby was born?
- ♦ Did you receive any information about planning for your health condition in the long-term? (e.g. what you need to know about your condition and for any future pregnancies? What you need to know about your condition as you grow older? What you need to talk with future doctors about your health condition?
- Was there anything you wished the <u>provider</u> had talked about at your postpartum visit but didn't? Looking back now, what would have been helpful?
- What do you wish you had been able to talk about but didn't? How did you feel when you left?
- What do you feel should be more of a concern for health care providers about women's health after they have a baby?

# **General Questions:**

- ♦ We talked a little about breastfeeding a minute a go. I am wondering if anyone had a breastfeeding challenge? What did you do? Where did you go? What helped to resolve that challenge?
- What if any messages have you heard about breastfeeding and safe sleep for the baby?
- ♦ What else have you heard about safe sleep?
- Were there any other health challenges you had after the baby was born? What did you do to get help for that? Where did you go?
- ♦ How confident are you that you understand your health condition and how it impacts your current and future health, including your future pregnancies?

- ♦ If you went to a new doctor, how prepared do you feel to describe and talk about your special health condition with him/her? And would you bring it up on your own or wait to be asked about your health history?
- ♦ What would help you feel more comfortable and confident to talk with a health care professional about your health needs and concerns? Can you think of any tools or resources which might be helpful in communicating your needs?

# VII. Brainstorming Parents of Newborns.

♦ Hand out Information for Parents of Newborns and AWHONN handout. Brainstorm creative approach to content and redesign.

Ask participants to review the AWHONN tool and ask who talked to them about this information?

How helpful would this information have been?

Hand out Information for Parents of Newborns

- ♦ Has anyone seen this document before? Moderator ask for hand count and counts aloud for recorder.
- ♦ Where have you seen it?
- Give participants about 5 minutes to read through the document. Then explain that it is required by law to be given to all new moms. Someone is supposed to go over with the mom and her support person. The state would like to redesign it and is looking for your input. So let's brainstorm ways to make it more useful. Explain that it can be something entirely different but something has to be given to the parent and review with them.

#### Closing

In closing, I would like to go around the room and have each of you share what is the most interesting thing you learned tonight?

Thank you for your time!

# HTMB Focus Group Guide: Preconception Men, Ages 18-25

# **X.** Introduction (5 minutes)

Moderator begins by introducing the concept, process, and purpose of the focus group.

- ♦ Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment
- ♦ Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements
- Explain why the group was selected to participate and encourage honesty.

**Purpose of group:** The purpose of this group is to discuss information related to the health concerns of men your age.

#### XI. Icebreaker

Moderator lays various picture cards around the room and on the table. She asks the group to take a moment to view as many cards as possible and choose the photograph that best illustrates where he is in life right now.

◆ Let's go around the room and share the picture you chose that describes where you are right now in life.

# XII. "My Health": Top of Mind, Priorities, and Behaviors (10 minutes)

Moderator lists answer on flip chart as she probes on the following questions.

- ♦ What do you think are the main health concerns for men your age? What are your own health concerns?
- ♦ What do you do to address these concerns?
- What stops you from doing some things you know you should do to address these concerns?
- ♦ Who do you talk to about your health concerns? Why?
- What did you see growing up with your fathers or uncles when it came to their health?
- ♦ What sorts of conversations do you have with women your age about their health and health concerns? *Probe*: Friends, girlfriends/partners, sisters?

# **Knowledge and Perceptions of Annual Physical**

- For what reasons have you gone to a doctor or a clinic in the past year or so? *Probe:* flu shot, sports physical, STD test, stress?
- What, if any health care providers have you talked to about your health. Tell me about those conversations. Were your concerns addressed? (Note to Moderator: many men in this age group do not have insurance so probe to determine what kind of provider health clinic? Private care? Or some may not have gotten care in the past few years – *probe for that as well)*
- ♦ When I say "annual physical" or "well exam," what comes to mind?
- Who here has had an annual physical? (Moderator takes count aloud for recorder) What prompted you to go?
- ♦ What happens at an annual physical?
- If you haven't had an annual physical, what have you heard about them?
- For what reasons do you think some men might not go for the exam? *Probe only if not* mentioned: What are some other barriers—transportation, insurance, don't want to go to a doctor's office, long wait for an appointment?
- If you were going to book an appointment tomorrow for an annual physical in (fill in community), where would you go? Why would you go there—service, past experience, reputation, cost, location? (Moderator tries to probe each participant)
- ♦ Just thinking of everything we've talked about concerning annual physicals what would make you more likely to go for your next exam or, if you haven't been, go for your first exam?
- What else would you need to know in order to schedule an annual physical appointment? *Probe:* a link to a simple website from Instagram with information about local providers, what happens at the exam, why you need it, a typical Q & A, and cost or insurance information?
- Where do you get information about staying healthy? *Probe*: Physical activity, healthy eating, mental health and emotional support? Do you talk to a provider, friends/family, online search, TV shows?
- ♦ Where do you get information about STDs?
- ♦ What do you know about birth control methods? Where do you get information about birth control? Who do you talk to about birth control? Probe: Parents, girlfriends/partners, healthcare providers, social media/online search?

#### XIII. Social Media

Okay now we are going to switch gears a bit and talk about how you get information.

- What social media are you most likely to use? Facebook, Instagram, Pinterest, Snapchat, others? (*Moderator captures the number of users for each of the following by asking participants to raise their hands if they are users.*) *Probe:* What social media platforms do you use the most?
- If you were trying to find out about what is going on socially (for the weekend or an upcoming event), which social media would you use? Or what ways would you find out what is going on?
- ♦ How do you like to listen to music? Local radio stations? Streaming services? Which ones? *Probe:* Do you hear ads when listening on these services or do you pay to have adfree access?
- ♦ What about TV, how do you watch TV cable? Netflix? Hulu? Probe for other
- ◆ Do you use any health-related apps? Which ones? (*Moderator takes count aloud for recorder*)

# **XIV.** Creative Testing (45 minutes)

The following health materials will be handed out for participants to review. We are now going to review some materials, some print and a couple of websites. I am going to give you a few minutes for each piece to review them. As you are looking through them, please note what you like or dislike about them, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

Give participants time to read through the following materials. Ask them to note anything they find interesting on their note pad.

- ❖ *Bedsider* contraception booklet #1
- \* Bedsider contraception booklet #2
- ♦ What did you learn that you didn't know before?
- What, if any, questions come up for you after reading those documents?
- ♦ What do you like or dislike?
- ♦ Which one are you the most likely to read? Why?
- ◆ In what format are you most likely to read this information? Facebook, App, website—or print?

#### **Health Text Campaign**

- What do you think about the idea of signing up for text messages about men's health? You would sign up and then get simple text messages twice a month with a link to learn more about men's health. Here are a couple examples. (Read sample texts as examples.)
  - o Text #1: You can get condoms for free. Find out how: [link]
  - O Text #2: Beat stress: exercising for 10 minutes twice a day helps you clear your mind and build your body: [link]

What kind of information might you find helpful to receive in these texts?

#### Websites (they will spend a few minutes on each site)

◆ First, how do you usually get online – on your phone or on a computer? How many of you have computers? (*Moderator will count hands aloud for the recording*)

Moderator hands out tablets or if participants prefer they can access the sites on their phone.

#### Young Men's Health Website

Moderator explains how to access youngmenshealthsite.org site. Moderator asks participants to take a few minutes to explore the site.

- ♦ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- ♦ What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

#### **Show Your Love Website**

Moderator ask participants to access Showyourlovetoday.com

- ♦ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?
- What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

# **Bedsider** Website

Moderator ask participants to access Bedsider.com

♦ Based on the first page whom do you think this web site is for? If you linked to this site how likely would you be to explore it? What did you look at first?

- ♦ What information was relevant to you?
- ♦ What did you like or dislike in terms of graphics and content?

Which of the sites based on style and content would you be most likely to go to? What kind of information would you like to see on a website like this?

Are there any other websites about men's health that you have visited in the past? What do you remember about those websites?

What other ideas do you have about making information available to men in your age group? How else would you like to get health information?

Any other places that you spend time at that should have men's health information available? *Probe:* gym, restaurants, movie theaters, auto parts stores like AutoZone? What if they had health information available? What would it look like?

Moderator gathers tablets.

# **XV.** Conclusion (10 minutes)

- OK, we are wrapping up. Just a few more questions. What do you think are the best ways to get the word out about a campaign about health for men your age? *Probe:* Social media, word of mouth, places in the community, schools? What about bus ads, have you seen any on the bus? Do you remember the messages in those ads?
- ♦ We have shown you a variety of materials from organizations like Show Your Love and Bedsider. Does it matter to you where this information comes from? If so, why?

Thank you for your time!

# HTMB Focus Group Guide: Fathers of Young Children

# **XVI.** Introduction (5 minutes)

Moderator begins by introducing the concept, process, and purpose of the focus group.

- Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment
- ♦ Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements
- Explain why the group was selected to participate and encourage honesty

**Purpose of group:** The purpose of this group is to discuss information related to men's health and fatherhood.

#### XVII. Icebreaker

Moderator ask each participant to introduce themselves and to share the name and ages of their children and to talk a little about themselves such as if they work or go to school.

Moderator lays various picture cards around the room and on the table.

- ♦ Take a moment to view as many cards as possible, and choose the photograph that best illustrates how you feel about your health right now at this time in your life.
- ♦ Let's go around the room and share the picture you chose and why.

# XVIII. "My Health": Top of Mind, Priorities, and Behaviors (10 minutes)

Moderator lists health concerns mentioned in previous exercise on white board and probes to determine what else men are concerned about.

- What do you think are the main health concerns for men your age? What are your own health concerns?
- ♦ What do you do to address these concerns?
- What keeps you from addressing these concerns?
- Who do you talk to about your health concerns? Mom? Girlfriend or friends? Dad? Etc.
- Where do you get information about staying healthy? *Probe*: Physical activity, healthy eating, mental health and emotional support? Do you talk to a provider, friends/family, online search, TV shows?

- ♦ When I say "annual physical" or "well exam," what comes to mind? What happens at an annual physical?
- ♦ Who here has had an annual physical? (*Moderator takes count aloud for recorder*) What prompted you to go?
- For what reasons do you think some men might not go for the exam?
- ♦ Who here has been to a doctor in the past year I'm not going to ask why just wondering who has been. Were your concerns addressed?

### IV. Social Media and Media habits

Okay now we are going to switch gears a bit and talk about how you get information.

- ♦ What social media platform are you most likely to use? Facebook, Instagram, Snapchat, others? (*Moderator captures the number of users for each of the following by asking participants to raise their hands if they are users.*)
- What do you use social media for? (keeping up with sports? Social reasons?)
- What about TV, do you watch regular network cable (moderator takes a hand count). What about streaming like Hulu, or Netflix? Take a hand count.
- ♦ How do you like to listen to music? Local radio stations? Streaming services? Which ones? *Probe:* Do you hear ads when listening on these services or do you pay to have adfree access?
  - ◆ Just thinking about your life in general, where do you go besides home and work? Probe: Gym, basketball court, coffee shop, brew pubs, in (San Antonio they said Monster truck shows) other.

## V. Being a Dad: Prenatal and Postpartum Exam Experience

Okay now we are going to switch gears again and talk about being a dad and we are going to look at some materials for dads

- Where do you go or who do you turn to for advice about being a dad? Probe: social media, websites, friends, family?
- ♦ Thinking about your youngest child, did you go to any prenatal doctor appointments with the mother? (Take hand count.) Tell me about that experience.
- ♦ How involved did you feel at those appointments? Did the doctors or nurses speak directly to you or ask you questions?

- ◆ Did you receive any brochures, handouts, or apps specifically from the doctor? Tell me about them. Were any just for dad?
- ♦ Please raise your hand if your child's mother went to a postpartum visit after the baby was born. *Moderator counts aloud for the recording*. Did you go with her to the postpartum visit? What happened at this visit? (Moderator may need to explain men in San Antonio did not know what a postpartum visit is.)
- ♦ I am wondering if anyone's partner had a breastfeeding challenge? What did she do? Where did she go? Did she get the information or support she needed?
- What, if any, messages have you heard about breastfeeding and safe sleep for the baby?
- ♦ What else have you heard about safe sleep? Where did you hear it?

# Knowledge and Behavior – Pregnancy Spacing

- ♦ What kind of family planning did you do?
- ♦ After you had your first baby, how did you decide when to have your next? What were some of the things you thought or considered?
- What do you think is a good space between babies? What makes you say that?
- Many experts recommend that women wait 18 months to 24 months before they get pregnant again. Why do you think that is a recommendation?
- ♦ How do you know about birth control methods? Where do you get information about birth control? Who do you talk to about birth control? *Probe*: Parents, girlfriends/partners, healthcare providers, social media/online search?

### Power Your Family Pamphlet

Moderator will pass out the pamphlet. I am going to give you a few minutes to review this pamphlet. As you are looking through it, please note what you like or dislike about it, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

- What are your top of mind thoughts about this information?
- ♦ What did you find relevant to you?
- ♦ What did you like or dislike about this pamphlet?

• How likely would you be to read this brochure if it was given to you by a health care provider?

# Bedsider Brochures (hand out both brochures)

- What are your top of mind thoughts about this information?
- ♦ What did you find relevant to you?
- What did you like or dislike about this pamphlet?
- ♦ How likely would you be to read one of these brochures if it was given to you by a health care provider? Which one?

#### **Bedsider Website**

Moderator will pass out the tablets and ask the participants to go to besider.com. Now I am going to give you a few minutes to review this website.

- What are your top of mind thoughts about this website?
- ♦ How relevant is this to you? Why do you say that?
- ♦ How likely would you be to use this website?

## Information for Parents of Newborns Pamphlet

Moderator will pass out the pamphlet. I am going to give you a few minutes to review this pamphlet. As you are looking through it, please note what you like or dislike about it, and then we will discuss your thoughts. We are looking to brainstorm creative approaches to redesign this piece to make it more relevant to mothers like you. We did not develop these materials, so whatever you say about them will not affect our feelings.

- ♦ What do you like about this piece? What do you dislike?
- What did you find relevant to you? Who do you think this pamphlet is for?
- ♦ What would you do to redesign this brochure?
- This piece has to have a printed component, what changes would you make to the printed version? Probe: plastic tip cards like from the breastfeeding bag? Folder with color-coded pull out cards?
- ♦ Would there be another way you would want to receive this information? Online? Phone number?

## Fathers Playbook App

Moderator will pass out the tablets and ask the participants to open the app. I am going to give you a few minutes to review this app. As you are looking through it, please note what you like or dislike about it, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

- ♦ What are you top of mind thoughts about this app?
- How relevant is this to you? Why do you say that?
- What do you like about this app? What do you dislike?
- How likely would you be to download an app like this?
- ♦ BABY CENTER: "How to hold a crying baby"

https://www.babycenter.com/2 how-to-hold-a-crying-baby 10408906.bc

- 1. What is the main message of the ad?
- 2. As a dad, is this relevant to you? Why or why not?
- 3. What, if anything, did you learn?
- 4. What are they asking you to do? Would you? Why or why not?

# **Dads Facebook Group**

Moderator show the news story video to the group:

https://abcnews.go.com/GMA/Family/facebook-group-helps-black-fathers-shatter-stereotypes-support/story?id=52857831

Moderator explains that even though the story focuses on black dads, the participants should consider the concept for all dads.

- ♦ How relevant is this to you? Why do you say that?
- ♦ How likely would you be to use a closed Facebook group like the one described in the story?
- Do any of you currently belong to any Facebook groups associated with parenting?

## VI. Conclusion (10 minutes)

Which of the things you've seen tonight would you like to learn more about?

Thinking back to our conversation about social media, or the places you hang out, what is the best way to get you information about the things you are interested in?

• In closing, please share one thing you heard tonight that was interesting or that you didn't know before.

# HTMB Focus Group Guide: Labor and Delivery Nurses

### I. Introduction

- Moderator begins by introducing the concept, process, and purpose of the focus group.
- Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment.
- Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements.
- Explain that all participants are nurses who work with mothers and newborns.

## II. Ice Breaker

Let's go around the group and introduce ourselves, tell us your position, where you work and for how long. Also, tell us what you like to do in your free time.

After introductions: Please pick a card from the picture cards in the middle of the table that expresses your feelings about working with patients who have a high-risk pregnancy.

# III. General Hospital Practice

- Who do you consider to be a high-risk maternity patient? What does the facility you work at consider to be a high risk maternity patient, is it different?
- I would like to go around the room one more time and have each of you explain your role in working with patients with high risk pregnancies.
- What are your hospital practices or protocols when it comes to caring for a woman who is considered a high-risk pregnancy? Do you have any special personal practices or protocols when it comes to caring for these women?
- How well do you think these practices or protocols are followed in your facility?
- Under what circumstances would they not be followed?
- What work are your hospitals engaging in to improve maternal health and safety?
- What barriers are there at your hospitals to offering more comprehensive care to women considered high risk?
- From your perspective, how knowledgeable are women about their high risk status and conditions as they impact their immediate health??
- How have you seen women effectively communicate about their health history? And how does that impact your approach to care with that patient, if at all?
- Where do you see gaps in the continuity of care from the outpatient prenatal care setting to the hospital for birth delivery?

- Then, where do you see gaps in the continuity of care from the inpatient setting (hospital) to the outpatient for these women?
- What kind of training have you received about addressing women who are considered to have a high-risk pregnancy? Did you learn it in school or from on- going education?
- How confident do you feel about your knowledge when it comes to managing care for high risk pregnancies?
- What tools or resources might be useful to you to increase your knowledge and comfort managing care for high risk women?

## **IV.** Patient Education

- Who do you think plays the most important role in educating patients who have a high-risk pregnancy about what to expect during delivery?
- What about after delivery?
- What tools or resources do you have to communicate with moms about their risk and what they need to do after giving birth and during the postpartum period?
- What tools or resources would you like to have?
- How are significant others and family members involved in education around high risk conditions?
- How prepared are women who had a high-risk pregnancy to go home to transition back into well care? Probe: What kind of resources are women given to connect them to care? How confident are you that they are getting that care?
- What barriers do you see in connecting women to community resources and well care services?
- What are some things that could be done to better support that transition back to well care services?
- From your perspective, how knowledgeable are women about their high risk status and conditions as they impact their long-term health status? Are they aware of how their current condition may impact (1) future pregnancies? (2) risks for future health complications/sequelae?
- How have you seen women effectively advocate for their health and health care needs? In what ways have you seen this self-advocacy change the care they receive, if at all?

## V. Creative brainstorming (this exercise may take up to 20 minutes)

Hand out Information for Parents of Newborns

• Has anyone seen this document before? Moderator ask for hand count and counts aloud for recorder.

- Where have you seen it? It is in their folder that they give them.
- Has anyone used it with patients? How?
- Give participants about 5 minutes to read through the document. Then explain that it is required by law to be given to all new moms. Someone is supposed to go over with the mom and her support person. The state would like to redesign it and is looking for your input. So, let's brainstorm ways to make it more useful. Explain that it can be something entirely different but something has to be given to the parent and review with them.
- Show participants the small information cards from the breastfeeding bag. Pass them around ask participants to look at them in pairs and then pass on.
- Show the materials from Bright Futures and pass them around.
- Encourage participants to think about what educational approaches they have seen that work.

Moderator record ideas on the flip chart. (Reminder for moderator. It can be something that is given out but can lead them to something online.)

To close out the exercise determine if there is one idea that seems to be the best.

# VI. Adjournment

We will close with these last questions – let's go around the group one last time and tell us two things:

- 1 –What did you hear tonight that made an impression on you?
- 2 What is the most important thing the health department can do to assist hospitals in addressing the needs of women with high risk pregnancies?

You've been a great group, thank you for your time!

# HTMB Focus Group Guide: Healthcare Providers

#### I. INTRODUCTION

- *Moderator begins by introducing the concept, process, and purpose of the focus group.*
- Lay ground rules for the discussion (no right or wrong answers, speak one at a time, etc.)
- Explain the purpose of the tape recording equipment
- Assure participants that their remarks are confidential in the sense that their names will never be attached to their statements
- *Introduce purpose of group:* The primary goal of this group is to hear your thoughts as a health care provider about women's health care.

#### II. ICE BREAKER

◆ Let's go around the group and introduce ourselves, tell a little bit about your practice (the size, number of patients you see in a day) and about the populations that you serve. Probe to determine the extent of patients who are of childbearing age.

## III. BACKGROUND AND GENERAL DISCUSSION WOMEN'S HEALTH CARE

- ♦ What kind of services do you provide for women that relate to well woman care?
- ♦ What about reproductive health?
- ♦ How important do you think it is to talk with women about their intentions about a future pregnancy? **Probe:** Does it come up with your patients? If so, tell me about it.
- What topics do you discuss related to future pregnancies and children? Probe: Birth spacing? Folic Acid? Breastfeeding? Risk Factors? Moderator writes the topics down on the white board.

### IV. Well Woman Health

- ♦ I'd like you to walk me through a typical well woman visit. **Probe:** (if the following aren't brought up) what about reproductive health, screening for risk factors, discussing healthy eating/nutrition?
- ♦ What about anxiety and depression? Do women bring it up? How do you make referrals to specialized providers? How confident are you that follow-up care is received?
- What tools or resources would help you talk about well woman health with your patients?
- What do you do to make women feel comfortable and to open up during a well women exam.
- How well do you think women know what is involved in a well woman exam?

• What do you think could be done to promote Well Woman exams?

## V. Prenatal to Postpartum Care

- Do you see women for prenatal visits? In the population you serve, do women typically enter into prenatal care in the first trimester or later on? Tell me about that. **Probe**: if late entry, ask why and what the perceived barriers are.
- Do many family members or partners accompany women in the prenatal visit?
- ♦ How do you encourage them to visit?
- Do you have any materials specifically for dad? Tell me about that?
- In your facility, do you offer prenatal group care (or centering)? If yes, how is it received by expecting moms? What do you see are the main benefits and challenges to this approach?
- ♦ Do you also see women for postpartum care? What percentage of the women in your care schedule and attend a postpartum visit? If not, what do you perceive as the barriers for that?
- I'd like for you to walk me through a typical postpartum visit.
- How do you address the following with your postpartum patients?
  - Reproductive life planning, birth control, healthy weight/nutrition, breastfeeding, safe sleep, folic acid, postpartum depression, anxiety....? What other issues frequently come up at this visit?
  - How frequently to partners or family members attend?
- What processes and communications are in place to support transitions for your patients between outpatient to inpatient care among different facilities and providers? Do you see any gaps?

### VI. High Risk and Care Coordination

- ◆ Tell me about your patients who are considered high risk. What are the most common risk factors of the women you see? *Moderator writes on the board*. (**Probing examples**: diabetes, hypertension, smoking, obesity, other chronic conditions, substance use)
- Which of these high-risk conditions are most alarming to you and why?
- For high-risk women who want to become pregnant, what role do you play in facilitating preconception and interconception services? Do you engage outside specialties (i.e., MRM, cardiology) for women with complex, chronic, genetic or other high-risk conditions?
- ♦ Who do you refer women with high-risk pregnancies to? How do you facilitate communication between providers? Give me some examples of how you communicate with specialty providers.

- For women with complex chronic conditions, how do you help them manage the transition to long-term management of their condition/well-woman care in the postpartum period?
- How connected do you feel with your referral network?
- ♦ Have you ever worked in a practice setting with a patient navigator (or similar)? What benefits or challenges with this have you seen.
- ♦ In general, how connected do you feel with other community and health care services in your area? (For example, social services, education, transportation, child care, mental health, WIC, home health). Do you, or someone else in your practice, help your patients identify these resources? How do you think these connections could be improved? **Probe:** would knowing more about these resources be helpful? How might you use that information?

### VI. Communication/Education

- From your perspective, how knowledgeable are women about their high-risk status and conditions? Probes: How well do you think they understand the implications of these risks for their health, including future pregnancies? How does understanding, or lack of it, affect their approach to planning for the future?
- ♦ How effective are your patients as health historians how many of them are able to share history about high-risk situations?
- How well do you think your patients advocate for their own health needs? Are some populations more engaged than others? Have you found any ways to engage or empower patients when they are not speaking up for themselves?
- ♦ How do you communicate and converse with pregnant women who have a complication like diabetes, or high blood pressure about what to expect and to look out for at birth and immediately postpartum? What has worked well for you in preparing these patients?
- ♦ Are there any materials or resources that you share with your patients who may have a higher risk of a maternal health issue? What kind of tools or resources would you like to have?
- Do you think women are able to effectively communicate with other health care professionals (e.g. nurses and doctors in the hospital, future doctors) about their risks? Have you found any way to help facilitate patients' communication with other providers?

# VII. Concepts/Creative Testing

We are now going to review some materials, concepts, and a website. I am going to give you a few minutes to review each of them. As you are looking through them, please note what you like or dislike about them, and then we will discuss your thoughts. We did not develop these materials, so whatever you say about them will not affect our feelings.

## **Moderator Introduces 'One Key Question'**

• Have you heard of 'one key question? What have you heard?

- Take providers to link for 'One Key Question'. <a href="http://onekeyquestion.org">http://onekeyquestion.org</a>
- Top of mind, what's your first reaction?
- How would you expect to use it in your practice? And what might be the benefits or challenges to having a conversation about pregnancy planning?
- Do you feel prepared to respond to the Yes? No? I Don't Know?

# Pregnancy/Birth Spacing.

- How do you talk to your patients about pregnancy spacing?
- In your opinion what is the appropriate birth spacing interval?
- How important is the birth spacing timeframe to a healthy baby? A healthy woman?

# Moderator distributes the 'Power you Family' Birth Spacing Pamphlet. Please review this pamphlet.

- ♦ What are your top of mind thoughts?
- Would this information would be useful to your patients?
- ♦ Would you be interested in having this as an educational tool to distribute to your patients? **Probe:** Why? Why Not?
- What is the best way to get materials to you and to your patients?

# Moderator shares 'PowermeA2Z.org' website with health care providers Directs them to the section of the website designed for providers.

- What are your top of mind thoughts about a website that offers these kinds of materials to providers like you?
- Is there any information that is new, or surprising?
- Would this information would be useful to you?
- Would you be interested if Texas had a site like this that you could direct patients to or that you could get information from?

Probe: Birth Control, Folic Acid, Breastfeeding, Birth Spacing.

If this doesn't work for you, what would be useful to you that you don't currently have? How would we get it to you?

# Are there resources, materials or tools that you have used or seen that are very effective you could tell us about?

In general, how do you stay up to date with available state resources and best practices?

Also, are there any special current maternal health issues and initiatives going on in Texas that you have heard of?

## VIII. Closing

♦ Thank you for your time! That was my last question for you. Would anyone like to share anything or comment about what we discussed today?

#### Interview Guide - Coalitions

Date:
nterviewer:
Coalition:
Person being interviewed:
Contact info:

Thank you for taking the time for a phone call. As I explained in my email, we want to learn about what your coalition has done so far and how DSHS could best support future efforts of the coalitions across the state. As part of this project, we will also be interviewing key stakeholders and experts, and conducting focus groups with women, men, and health care providers. (Let them know if one will be taking place in their community and that they will be invited to observe.)

This is a confidential conversation. That means what you say will <u>not</u> be connected with your name, but it may be associated with your coalition. This is not a test; there are no right or wrong answers. We know the coalitions are at different stages of development and we will not be judging them against each other. If you do not know the answer to one of my questions, something does not apply, or you would rather not answer, just say so. The interview should take about an hour.

Do you have any questions for me before we start?

# I. Background Information

1. Would you please tell me about your coalition? How was it formed? What is your role? Probes:

How long have you been in operation?

How are you organized?

- Leadership?
- Core group?
- Committees?
- How often do you meet? Attendance?

How satisfied are you with the diversity of the members? Would you like membership to be different in any way? How?

How have you engaged local partners?

Biggest successes so far?

Any challenges?

## **II. Coalition Strategic Priorities**

2. I understand that over the first year of the contract with DSHS, the coalitions have been working on a local needs assessment and strategic plan. (If applicable: I've had a chance to see your plan so I know a little about your goals.) In your own words, what are your coalition's priorities?

## III. Audience and Priority Population

3. What population or populations are or will be your primary focus? Describe your priority population(s). What do you know about this audience?

Probe: what do you perceive about the needs, barriers, strengths and opportunities inherent in this population. How do you know this?

4. What approach are you taking or do you plan to take? What specific behaviors are you asking people to change? What are the calls to action? (May vary by population.)

# IV. Reaching Priority Populations

5. How do you currently reach and engage these populations? What outreach, communication and engagement strategies and resources have you dedicated previously (or currently) to reach this audience/population? What messages and tools, for example, websites, written materials, apps are you using now, or considering using?

Probe: How has that worked or not worked in helping to meet your goals? What were those strategies' strengths/weaknesses?

What do you believe are the best ways to reach your populations?

What resources are you missing or need to reach your audience?

6. Have you used DSHS resources, like Someday Starts Now or other resources/materials?

Probe: How did you use it? What was your experience with that? What was useful/not useful/what was missing?

7. Aside from your priority populations, do you have strategies for any of the other populations our study is focusing on: young men who are not parents, fathers, women who have not had a baby, interconception health, women with high-risk pregnancies, health care providers? What are your plans?

### IV. Focus Groups

- 8. I mentioned that as part of this project we will be doing focus groups. We will be talking with:
  - Young women who have never had a baby (preconception health)
  - Women who have recently given birth
  - Women who have had a high-risk pregnancy
  - Young men who are not parents (preconception)
  - Men whose partner recently gave birth
  - Heath care providers who specialize in obstetric care
  - Nurses (who work in preconception, interconception, maternity and postpartum care)



Thinking about your coalition's goals and your priority populations, what would you like to learn from the focus groups? Anything specific you would you want us to ask any of those groups?

9. Are there any messages, materials, concepts, or approaches you would like us to test with the participants in any of our focus groups?

# V. Open Ended Questions

- 10. We know you have different audiences, but if you had ONE overarching message, what would it be? Who would the audience or audiences be?
- 11. If you imagine a statewide DSHS Healthy Texas Mothers and Babies campaign, what might it look like and how might your Coalition tap into it?
- 12. If you envisioned a perfect network for the coalitions across the state, what would that look like? What kind of support, resources would be most helpful in this network?
- 13. Anything else you want to say? Anything I did not ask that might be helpful to us or DSHS?
- 14. Who else from your coalition would be a good person for me to talk with? Someone who might have a different perspective, for example, a community member or partner actively engaged with the coalition. (Get contact info and ask the person being interviewed to give them a heads up that we will be contacting them.)

Thank you so much for your time and ideas.

## Interview Guide - Key Stakeholders

Date:
Interviewer:
<b>Coalition:</b>
<b>Person being interviewed:</b>
Contact info:

Thank you for taking the time for a phone call. As I explained in my email, we are working with DSHS to help them learn how to best support the efforts of the Healthy Mothers and Babies initiatives, coalitions and stakeholders across the state. As part of this project, we are interviewing key stakeholders such as yourself. We are also conducting focus groups with women, men, and health care providers in six locations. (Let them know if one will be taking place in their community and that they will be invited to observe.) We are interested in hearing different perspectives about the needs and gaps.

This is a confidential conversation. That means what you say will <u>not</u> be connected with your name. This is not a test; there are no right or wrong answers. If you do not know the answer to one of my questions, something does not apply, or you would rather not answer, just say so. The interview should take about an hour.

Do you have any questions for me before we start?

# I. Background Information - Ask All

15. Would you please tell me a bit about what you do? What is your interest and role in maternal and child health?

# II. Questions for Stakeholders Involved in Programs

- 16. What program or programs are you involved in? Which if any DSHS programs/initiatives are you involved in? And what is your role?
- 17. What are your programmatic priorities and goals? Probes: How satisfied are you with your progress? What do you hope to address next?
- 18. Tell me about your priority populations. What groups are you trying to reach? Probe: What are the most important things you have learned from or about these populations? Are there things you wish you understood better about these populations?
  - 19. What are the key messages for your audiences? What behaviors are you trying to change?
  - 20. How have you reached out to those audiences? How well have your outreach or education strategies worked? (**Probe for successful strategies and best practices**) Anything else you plan or hope to try?

21. Thinking about women's (**or Men's**) health, and ultimately healthy babies, are there unmet needs? What do you see as the biggest issues that are not being addressed or not being addressed successfully? What are the barriers?

### **III. Questions for Clinicians**

- 22. What population or populations do you interact with **in your clinical practice**? What are the most important things you have learned from or about these populations? Are there things you wish you understood better about these populations?
  - 23. From the clinical perspective, which groups do you think are being reached successfully? Which are not being reached?

    Probes:
    - What populations are you seeing come in for care, and which are not? What do you think it would take to reach them?
    - Which populations do you think are getting health messages and information, and which are not?
  - 24. How well do you think your patients advocate for their own health needs? Are some populations more engaged than others? Have you found any ways to engage or empower patients when they are not speaking up for themselves?

# IV. State-wide Campaign – Ask All

- 25. DSHS is working to update and rebrand their healthy mothers and babies awareness campaign. What do think are the most important messages at the state level?
- 26. Who should the priority audiences be?
- 27. What do you think would be the best way to reach those audiences?
- 28. If you envisioned a perfect network of partners and stakeholders all working to improve the health of women and children, what would that look like?

#### Probe:

How do you envision yourself and your work fitting in?

How could you or would you like to contribute?

How do you envision being linked?

What kind of support, resources would be most helpful in this network?

### V. Focus Group Pop – Ask All

- 29. I mentioned that as part of this project we will be doing focus groups. We will be talking with:
  - Young women who have never had a baby (preconception health)
  - Women who have recently given birth

- Women who have had a high-risk pregnancy
- Young men who are not parents (preconception)
- Men whose partner recently gave birth
- Heath care providers who specialize in obstetric care
- Nurses (who work in preconception, interconception, maternity and postpartum care)

Anything specific you would you want us to ask any of those groups? Are there any messages, materials, concepts, or approaches you would like us to test with the participants in any of our focus groups?

(Note: we will ask this question only if the interview is before the focus groups.)

# V. Open Ended Questions – Ask All

- 30. We know you have different audiences, but if you had one overarching message, what would it be? Who would the audience or audiences be?
- 31. What kind of materials, resources or tools would be most helpful to you to better inform and engage the priority populations you work with?
- 32. Anything else you want to say? Anything I did not ask that might be helpful to DSHS?

Thank you so much for your time and ideas.