The Advancing Health in South Texas Engagement Series: *What Matters to You?*

Summary Report

April, 2016

Methodist Healthcare Ministries OF SOUTH TEXAS, INC.
"Serving Humanity to Honor God"

Health Resources in Action
Advancing Public Health and Medical Research

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EXECUTIVE SUMMARY

Background

In the fall of 2015, Methodist Healthcare Ministries of South Texas, Inc. was awarded the Eugene Washington PCORI (Patient-Centered Outcomes Research Institute) Engagement Award to implement a project titled *Advancing Health in South Texas Engagement Series.* Through this award Methodist Healthcare Ministries will convene patients and key stakeholders across a 20-county area to develop a coordinated regional approach for patient-centered research and evaluation among university systems, academic institutions, managed care organizations (MCOs), and public health systems. Actionable and measurable engagement will be used in creating a clear and intentional framework to guide system alignment and ensure authentic patient engagement in the future dissemination of research and evaluation findings.

In 2015, Methodist Healthcare Ministries partnered with Health Resources in Action (HRiA), a non-profit public health organization, to serve as the series facilitators to identify appropriate patient engagement models for the region. In February 2016, Methodist Healthcare Ministries and HRiA facilitated the first of the engagement series: ***What Matters to You?*** The session consisted of six, two-hour focus groups across the upper and lower Rio Grande Valley and the Coastal Bend areas, where rates of chronic disease and related mortality among the population exceed those in most other regions of the state and the nation (Fisher-Hoch et al., 2012; Davila, Rodriguez, Urbina, & Nino, 2014).

Methods

Focus groups were used as the strategy to obtain in-depth accounts of community members' experiences with healthcare and dissemination strategies in this 20-county area (Figure 1). Six, two-hour groups with 73 individuals (17 men, 56 women) were convened in February 2016 in: Nueces, Zavala, Jim Wells, Hidalgo, Cameron, and Webb counties. The groups were facilitated in English (n=2 groups) and Spanish (n=3 groups), as well as bilingually (n=1 groups), depending on the preference of the participants. The focus groups spanned across age groups, geography, and participants' role in the community.

Findings

<u>Resilient Communities Strengthened by Strong Cultural Ties</u>

- Though focus groups spanned a mixture of rural and metropolitan cities, participants frequently described their communities as **friendly, "tight-knit"** and **united.**
- **Shared cultural beliefs** and traditions resonated as strong **community assets** for focus group participants. Values such as **hard work** and **a devotion to one's family** were described as core principles in the predominantly Mexican-American communities.
- Focus group participants described being **actively engaged** in their **political** and **civic environment**. Residents across all six groups described volunteering and fundraising for issues and organizations they cared deeply about.

Socioeconomic and Environmental Factors Negatively Impact Health

- Focus group participants described social and environmental concerns including **poverty, crime and safety, employment, and transportation** barriers among the most concerning.
- Across groups, residents reported that the **cost of healthcare was the biggest financial burden** to families and communities in the region.
- Focus groups members **generally spoke positively about their surroundings**, noting that many of the communities in the region had access to parks and recreational activities. Yet across geographies, residents described a desire for more structured after-school activities and community events to keep youth busy.
- Nueces, Zavala, and Jim well counties were described as areas strongly impacted by the **declining oil industry**, with some residents describing their communities as "*ghost towns.*"
- In border regions more so than other groups, participants described **seeking care across the border in Mexico**. Participants described **better care coordination, timeliness, bedside manner, and higher quality care across the border**.
- **Specialty care** such as cancer treatment and dental check-ups were the most commonly reported to be sought in Mexico. The cities of Matamoros, Reynosa, and Nuevo Laredo were the most frequently cited cities for routine care.
- While many who sought care across the border reported being content with the quality of care they received, concerns were raised about the **increasing risks** of routinely crossing the border for healthcare. As one resident noted, "*I'd rather take the risk and drive across the border for care. You'll die waiting for an appointment before doctors will see you here* [resident's community in the Valley]."

High Burden of Chronic Diseases and Risk Factors

- Apart from socioeconomic factors, focus group participants described a high burden of chronic diseases and their risk factors-- **mainly diabetes, cancer, and substance abuse** as significant concerns that impact many residents.
- Mental health issues including **stress** and **anxiety** were frequently cited as challenges among participants.
- **Substance abuse** was mentioned in every focus group, with participants concerned about a range of substances ranging from marijuana to opioids.
    - Synthetic marijuana known as "K-2" was mentioned in three of the groups, in Nueces, Jim Wells, and Webb counties.
- Participants were particularly concerned **about co-occurring instances of mental health and substance abuse issues among youth**.
- Focus group participants described **healthy eating** and **physical activity** as ways to stay healthy, but cited a **lack of health literacy** and **affordable recreational programming** in their communities.

- Focus groups participants expressed concern over the lack of community resources around **sexual health, particularly for youth.**

Difficulty Navigating a Complex Health System

- Most focus group participants cited receiving care at **federally qualified health centers, mobile health clinics, emergency rooms,** and **urgent care centers.**
- Across geographies, participants reported a healthcare system that was **confusing** and **inaccessible** saying, "*Everything is in acronyms. Terminology is a big problem…they might as well be speaking in Greek. I need to know what they are actually saying in layman's terms so I don't feel stupid*."
- Among all six groups, participants described having to **leave their communities** in order to receive quality health care. Residents in the Coastal Bend area cited having to drive between 1-4 hours to receive care in larger cities such as Corpus Christi, San Antonio, and Houston, where they perceived to have more engaged providers.
- Focus group participants universally agreed that **the time it took to access care** was a major problem in the region. Residents described waiting for up to six hours in the emergency room before being seen for ailments including: chest pain, a poisonous bite, and diabetic symptoms such as numbness of the limbs.
    - Many participants reported **navigating long wait times by traveling to Mexico** for care, or attempting to treat ailments with **over the counter or home remedies.**
- Across geographies, many focus group participants agreed that they **would not seek care for a general issue** such as the common cold or an ear infection. For more severe health problems, most participants sought care at **hospital emergency rooms** or **private urgent care clinics.**
- **Insurance barriers** were also attributed to the **over-utilization of emergency rooms**. As one participant noted, "*People go to the ER because they don't have insurance. When you go to the doctor you have to pay a co-pay, and for people who can't afford it, they'll go to the ER because they're not charged immediately."*
- There were **mixed opinions regarding care coordination** throughout the region. Residents in Webb County praised their care coordination and noted, "*There is always a willingness to share resources to provide better services for those in need."*
- On the contrary, residents in the Coastal Bend and Rio Grande Valley described their care as **fragmented** and **uncoordinated**. In Nueces County, residents voiced mistrust of the hospital system, with several participants sharing stories of being denied care because they were homeless.
- Focus group participants across all groups commented that they believed doctors were over-**medicating and over-testing residents**. Participants perceived that doctors ordered unnecessary testing, as one example from a participant: *"I got sent to a specialist and they ordered the exact same tests I took two days before.*"
- Many residents thought **money** was the driving factor behind their concerns. As one participant noted, "*Doctors took an oath to care for the person, not to get rich off of their illnesses."*

Residents Prefer a Mixed-Method Strategy for Receiving Health and Research Information

- A **mixed communication strategy** including in-person interactions, flyers, local radio, and community events were the most frequently suggested ways to disseminate information to the masses. However, focus group participants stressed the importance of **understanding the unique communities** being engaged before disseminating health information.
- **Oral** or **written communication** preferences varied between municipalities, but **word-of-mouth** and the **internet** were reported as the most trusted sources to receive health-related information.
- Very **few focus group participants were aware of new research** studies or treatment options in their communities. Residents who were aware of research studies were engaged with the local universities in some capacity, whether through employment or attending university-sponsored events.
- Of the few participants who reported participating in clinical trials, **none** of them were told about the **results of the study**, which frustrated many.
- When asked what questions participants would have if a doctor asked them to be part of a new research study, the majority of focus group participants said knowing **the side effects** and **success rates** were most important.
- Participants expressed frustration over **complicated medical jargon** and acronyms and stressed the **importance of considering literacy levels and terminology** when disseminating health-related information. Providing a lay summary of study findings in **both English and Spanish** were strategies mentioned by focus group participants.
- Participants reported making healthcare decisions based on how much **trust** they had in their providers. Residents described trust as a bridge to active engagement by creating and maintaining **mutual respect.**
- **Continuous partnering** with the community through **group discussions and focus groups** were described as ways to keep community members engaged throughout the research process. Further, participants described the importance of **engaging family members** in discussions around health and new treatment options.
- **Community Health Workers** were reported as highly trusted among focus group participants. Residents suggested partnering *promotores* with community champions in order to engage hard-to-reach residents.
- **Trusted organizations**, whether faith-based or community-based, were described as **gatekeepers** between healthcare providers and community residents, and should be engaged in future dissemination strategies.

> **"It's a cultural thing…people need to understand our food, our language, our traditions."-Focus Group Participant**

COMMUNITY RECOMMENDATIONS

Community residents provided valuable feedback for areas of improvement related to the health systems and health information dissemination strategies. The following sections highlights the community recommendations that were common across the six focus groups:

More Engaged, Culturally Competent Health Education. Focus group members were interested in more access to health literacy resources including nutrition classes and preventive health **available in both English and Spanish**. Residents also stressed the importance of **engaging, culturally-appropriate health literacy** options. Many women mentioned enjoying Zumba and nutritional classes that focused on Hispanic foods, saying "*They need to understand the cultural environment we come from and approach the audience from our perspective*."

More Information and Navigation Around the Health Care System. A prominent theme across focus groups was the need to break down barriers to navigating the complex health system. Focus group members spoke about the **struggle understanding their healthcare benefits**, and often found that they were being charged for treatments that were not covered by Medicaid and private insurance. In the words of one resident, "*I have rights as a patient. I want to know how the medications I'm being prescribed will interact with my other medications. I want to be told about options that I qualify for and why they are better or worse."* Focus group participants also shared the desire for more in-person discussions with their peers, noting: *"If we had groups like this more frequently we could learn a lot from each other."*

Patient Empowerment. Focus group participants voiced many concerns about **patients being afraid to speak openly and honestly** with healthcare providers. A strategy to reduce this fear, said one participant, "*Is to change the patient perspective.*" A clinic provider described how nurses could encourage patients, saying "*My elderly patients are very timid to ask questions because they think the doctor is very busy and doesn't want to take up his time. I try to turn the table and say 'you're his boss, the doctor is working for you so you need to make sure you get what you need from him.'*"

Support for Youth. Participants frequently mentioned the need for more youth services and recreational activities in their communities. Across regions, there were many concerns about how young people were occupying their free time, with residents in rural areas saying: "*They have nothing to do after school, so they get tempted and try things like drugs.*" Sexual health in schools and the community were also mentioned as key issues to focus on. Residents were interested in their children knowing more about **healthy relationships, contraception, and sexually transmitted infections.**

Support for Seniors. The aging population was recognized as vulnerable and disenfranchised, with one resident saying, "*All elderly patients should have a patient advocate with them at the doctor's office. I see so many patients who are mistreated and neglected just because they're old.*" Many participants envisioned a community where the elderly had access to transportation, homebound services, and patient navigators.

Community Champions. Many participants, namely in the Coastal Bend area, described the need for "*an initiator*" in the community, someone who was trusted and could mobilize members to participate in healthy-living activities. In the Rio Grande Valley, residents described partnerships between community health workers and **neighborhood champions** that could improve patient turn-out at mobile health clinics in *colonias*.

Language and Medical Explanations. Many residents described the need for written and oral medical explanations to be simplified in a language that they understood. This meant eliminating acronyms and medical jargon, as well as having information available in both English and Spanish. Further, there was strong agreement about **including family members in health-related discussions**, particularly when it involved elderly patients.

Mutual Aid. Focus group participants described a system of care in which those receiving services and those providing them could be more **integrated.** As one participant noted, "*We can give back to the state by cleaning up the area in return for care. Something where both sides can come to an agreement and benefit."*

Mixed-methods Communication Strategy. As previously discussed, participants across geographies preferred a mixed-method communication strategy, with most preferring face-to-face interactions. A key suggestion was that: "*People in different cities get their information from different sources. You have to find out where they hang out and who they talk to, then you will know how to best communicate with them."*

"If *promotoras* worked with the leaders in *colonias* they would have more success reaching residents who aren't engaged." –Focus group participant

INTRODUCTION

Methodist Healthcare Ministries of South Texas, Inc. is a private, faith-based, not-for-profit organization dedicated to providing medical, dental and health-related human resources to low-income families, the uninsured and underinsured in 74 counties across South Texas, approximately one-third of the state. The mission of Methodist Healthcare Ministries is "Serving Humanity to Honor God" by improving the physical, mental and spiritual health of those least served. The mission is achieved through programs owned and operated by Methodist Healthcare Ministries as well as strategic investments to non-profit partners with similar missions. Since its founding in 1995, Methodist Healthcare Ministries has provided more than $600 million in healthcare services through its own clinics and programs as well as through funding to its community partners.

In the fall of 2015, Methodist Healthcare Ministries was awarded the Eugene Washington PCORI (Patient-Centered Outcomes Research Institute) Engagement Award to implement a project titled *Advancing Health in South Texas Engagement Series.* Through this award, Methodist Healthcare Ministries will convene patients and key stakeholders across a 20-county area to develop a coordinated regional approach for patient-centered research and evaluation among university systems, academic institutions, managed care organizations (MCOs), and public health systems. Actionable and measurable engagement will be used in creating a clear and intentional framework to guide system alignment and ensure authentic patient engagement in the future dissemination of research and evaluation findings. The Engagement Series will focus on the Rio Grande Valley and Coastal Bend regions, including: Cameron, Hidalgo, Starr, Willacy, Kenedy, Brooks, Jim Hogg, Zapata, Duval, Jim Wells, Kleberg, Webb, Nueces, San Patricio, Aransas, Refugio, Bee, Dimmit, Zavala, and Maverick counties.

As part of the engagement series, Methodist Healthcare Ministries has partnered with Health Resources in Action (HRiA), a non-profit public health organization, to serve as the series facilitators to identify appropriate patient engagement models for the region. There are currently five meetings planned in this engagement series that will be held within the next two years. Each session will build upon the previous, ensuring that various perspectives are reflected in a common agenda throughout the PCORI project. The initial session of the engagement series, ***What Matters to You?,*** consisted of six community focus groups meant to serve as the project foundation in order to frame and contextualize future discussions. Through this process university systems, academic institutions, managed care organizations (MCOs), and public health systems will engage in meaningful dialogues that are guided by authentic patient feedback.

In February 2016, Methodist Healthcare Ministries and HRiA facilitated six, two-hour focus groups across the upper and lower Rio Grande Valley and Coastal Bend area, where rates of chronic disease and related mortality among the population exceed those in most other regions of the state and the nation (Fisher-Hoch et al., 2012; Davila, Rodriguez, Urbina, & Nino, 2014). Seventy-three South Texas residents were engaged in discussions to gather meaningful feedback regarding: what patients identify as important health issues for their communities; how these issues are communicated to them; and solutions to feel actively engaged in co-constructing solutions. The following report summarizes the findings and common themes of **The Advancing Health in South Texas Engagement Series: *What Matters to You*?** Findings from this report will help guide further discussions throughout the project with academic researchers, healthcare leadership, public health leadership, and other stakeholders.

APPROACH AND METHODS

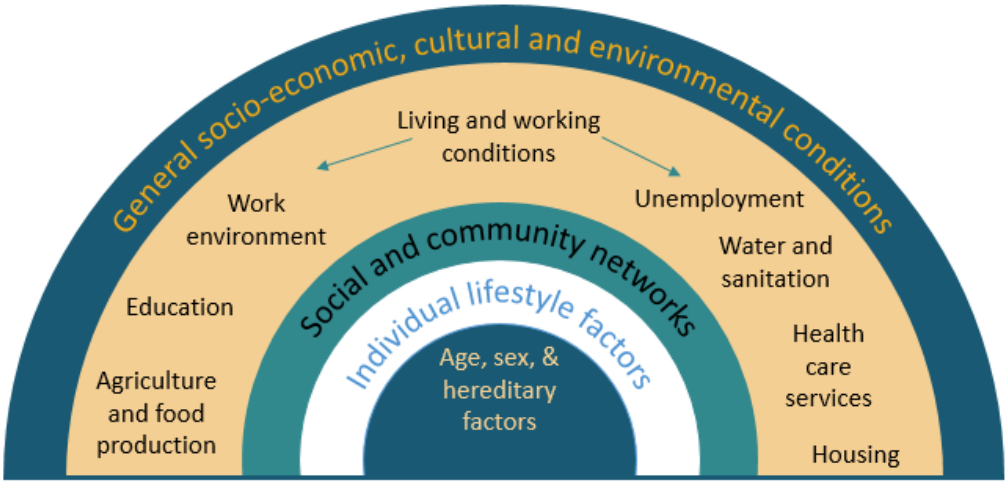
The following section describes how the data for the summary report were compiled and analyzed, as well as the broader lens used to guide this process. Specifically, the engagement series defines health in the broadest sense and recognizes that numerous factors at multiple levels impact a community's health — from lifestyle behaviors (e.g., diet and exercise), to clinical care (e.g., access to medical services), to social and economic factors (e.g., employment opportunities), to the physical environment (e.g., air quality). The beginning discussion of this section discusses the larger social determinants of health framework which helped guide this overarching process.

Social Determinants of Health Framework

It is important to recognize that multiple factors have an impact on health, and there is a dynamic relationship between real people and their lived environments. Where we are born, grow, live, work, and age—from the environment in the womb to our community environment later in life—and the interconnections among these factors are critical to consider. That is, not only do people's genes and lifestyle behaviors affect their health, but health is also influenced by more upstream factors such as employment status and quality of housing stock. The social determinants of health framework addresses the distribution of wellness and illness among a population. While the data to which we have access is often a snapshot of a population in time, the people represented by that data have lived their lives in ways that are constrained and enabled by economic circumstances, social context, and government policies. Building on this framework, this assessment approaches data in a manner designed to discuss who is healthiest and least healthy in the community, as well as examines the larger social and economic factors associated with good and poor health.

Figure 1 provides a visual representation of this relationship, demonstrating how individual lifestyle factors, which are closest to health outcomes, are influenced by more upstream factors such as employment status and educational opportunities. This report provides information on many of these factors, as well as reviews health perceptions among the residents in Methodist Healthcare Ministries' service area.

Figure 1. Social Determinants of Health Framework



DATA SOURCE: World Health Organization
NOTE: Graphic adapted by Health Resources in Action

Qualitative Data

Focus groups were used as the strategy to obtain in-depth accounts of community members' experiences with healthcare and dissemination strategies in this 20-county area (Figure 1). Six, two-hour groups with 73 individuals (17 men, 56 women) were convened in February 2016 in: Nueces, Zavala, Jim Wells, Hidalgo, Cameron, and Webb counties. The groups were facilitated in English (n=2 groups) and Spanish (n=3 groups), as well as bilingually (n=1 groups), depending on the preference of the participants.

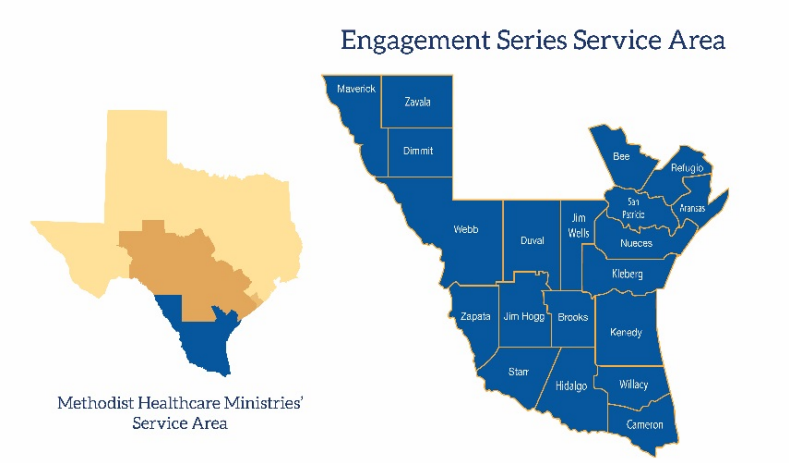
The focus groups spanned across age groups, geography, and participants' role in the community. Methodist Healthcare Ministries partnered with trusted community organizations to help identify and recruit subsets of the population that would offer unique perspectives of community health. The intentional recruitment of target populations ensured that the focus groups represented a range of perspectives, including those of: the self-described homeless population; community residents receiving care at a Federally Qualified Health Center (FQHC); rural healthcare providers and patients in the Coastal Bend area; and Rio Grande Valley *colonia* residents, which are defined as unincorporated settlements of land along the border that may lack some of the most basic living necessities, such as drinking water, sewer systems, electricity, and paved roads. Table 1 describes the target populations identified by Methodist Healthcare Ministries and community partners for each of the focus groups in the ***What Matters to You?*** engagement series.

Table 1. Methodist Healthcare Ministries Focus Group Recruitment Partners and Target Populations

Community Partner:	Target Population:
Corpus Christi Metro Ministries- Nueces County (Corpus Christi, TX)	Self-described homeless adults
Vida y Salud- Health Systems- Zavala County (Crystal City, TX)	Community residents receiving care at a federally qualified health clinic (FQHC);
Mercy Ministries of Laredo- Webb County (Laredo, TX)	Community residents receiving care at a federally qualified health clinic (FQHC)
Rural Economic Assistance League (REAL) - Jim Wells County (Alice, TX)	Rural healthcare providers and patients in the Coastal Bend area
La Unión del Pueblo Entero (LUPE) – Hidalgo County (San Juan, TX)	Upper Rio Grande community members living in *colonias*
Proyecto Juan Diego- Cameron County (Brownsville, TX)	Lower Rio Grande community members living in *colonias*

All focus groups followed the same procedures, including a semi-structured focus group guide and the same facilitator to ensure consistency in the topics covered. Participants received a $50 gift card after completing the 90-120-minute focus group. The groups were audio recorded, and notes were taken in-person to account for group dynamics and body language. The content was then analyzed by the Health Resources in Action (HRiA) team. No names or identifying details were used in this analysis.

Figure 1. PCORI Engagement Series Service Area



Analyses

The collected qualitative information was manually coded and then analyzed thematically for main categories and sub-themes. Data analysts identified key themes that emerged across all groups as well as the unique issues that were noted for specific populations. Frequency and intensity of discussions on a specific topic were key indicators used for extracting main themes. While municipality differences are noted where appropriate, analyses emphasized findings common across the greater South Texas region. Selected paraphrased quotes – without personal identifying information – are presented in the narrative of this report to further illustrate points within topic areas.

Limitations

As with all data collection efforts, there are several limitations related to the engagement series' methods that should be acknowledged. Data based on self-reports should be interpreted with caution. In some instances, respondents may over- or underreport behaviors and illnesses based on fear of social stigma or misunderstanding the question being asked. In addition, respondents may be prone to recall bias—that is, they may attempt to answer accurately but remember incorrectly.

While efforts were made to talk to a diverse cross-section of individuals, demographic characteristics were not collected from the focus group participants, so it is not possible to confirm whether they reflect the composition of the region. The focus group findings represent a sub-set of community residents, with more women participants (77%) than men (23%), and may be limited in their generalizability.

Recruitment for focus groups was conducted by community organizations, and participants were those individuals already involved in community programming. Therefore, participants in the focus groups may be prone to selection bias – that is, individuals who had more positive experiences may have been more likely than other individuals to participate.

While the focus groups conducted for this study provide valuable insights, results are not statistically representative of a larger population due to non-random recruiting techniques and a small sample size. Lastly, it is important to note that data were collected at one point in time, so findings, while directional and descriptive, should not be interpreted as definitive.

COUNTY FINDINGS

The following section provides in-depth descriptions of the common themes outlined in the executive summary. The substantiation of common core themes and variations are expressed by each county below:

Resilient Communities Strengthened by Strong Cultural Ties

"The Hispanic culture is one *where the **family is at the center** of everything." –Focus group participant*

Though residents in Southern Texas encounter numerous social and economic challenges to health including poverty and barriers to access, focus group participants shared stories of **resilience** and **community cohesion strengthened by strong cultural ties** that can be leveraged upon in future dissemination strategies. Residents described their communities as friendly, "tight-knit" and united. Values such as hard work and a devotion to one's family were described as core principles across the six groups. Further, participants commonly **attributed culinary norms to poor health behaviors** and outcomes, noting that: "*There are certain cultural things that we can't get rid of…the tamales and the tortillas that we love so much."*

- **In Nueces County (Corpus Christi, TX):** Participants described community cohesion amongst fellow residents who were homeless, particularly around the exchange of mutual aid around issues of safety, and transportation.
- **In Webb County (Laredo, TX):** Webb County residents reported civic engagement as a strength in their communities. Participants described volunteering at federally qualified health centers during their spare time. Residents were engaged with faith organizations and reported volunteering at Mercy Ministries of Laredo.
- **In Zavala County (Crystal City, TX):** Residents described their community as friendly, "*tight-knit*" and united. Participants also indicated that they felt supported by fellow community members through mutual aid, childcare, and transportation.
- **In Cameron County (Brownsville, TX):** Residents in Cameron County were less likely to report a sense of strong community cohesion, saying, "*I don't know any of my neighbors. We all keep to ourselves in around here.*" However, residents described strong cultural ties that united community residents.
- **In Hidalgo County (San Juan, TX):** Participants in Hidalgo County described a strong sense of political engagement, especially around issues affecting *colonia* residents. Several *colonia* residents celebrated their recent victory of the new ordinance that gave their neighborhood access to electricity, noting "*Now we have light, and I want other colonias to organize and be able to do the same."*
- **In Jim Wells County (Alice, TX):** Residents described their community as "tight-knit" and friendly, stating, *"We all love to come together to support our kids. I see a lot of parents at academic and athletic events, and I love how involved and supportive everyone is."*

"We are a united community—when someone needs help we all come together." –Focus group participant

Socioeconomic and Environmental Factors Negatively Impact Health

"The increase of drugs has affected everyone; there's more crime and vandalism than ever before."
–Focus group participant

Focus group participants described social and environmental concerns including **poverty, crime and safety, employment, and transportation** barriers among the most concerning. Across groups, residents reported that the cost of healthcare was the biggest financial burden to families and communities in the region. In border regions more so than other groups, participants described seeking care across the border in Mexico, many times having to discontinue treatment due to financial barriers. Further, Nueces, Zavala, and Jim Wells counties were described as areas strongly impacted by the **declining oil industry**, with some residents describing their communities as "ghost towns."

- Focus groups members generally spoke positively about their surroundings, noting that many of the communities in the region had access to parks and recreational activities. Yet across geographies, residents described a desire for more **structured after-school activities** and **organized community events** to keep youth busy. As one participant said, "*Our community needs more positive outlets to keep youth off the streets and away from drugs."*
- **In Nueces County (Corpus Christi, TX):** Residents in the Coastal Bend area described crime and safety, exacerbated by substance abuse, as their biggest concern. Residents who resided in the outskirts of the county described transportation barriers that affected employment and healthcare compliance.
- **In Webb County (Laredo, TX):** In Webb County, residents described vandalism and theft as the most prominent crime see in their communities. As one participant noted, "*We have beautiful parks that are defaced every few weeks."* Transportation was reported as a barrier to care, especially for elderly patients. One Webb County resident described having to travel two hours by bus to get from her house to the clinic, 20 miles away.
- **In Zavala County (Crystal City, TX):** Nearly all group participants in rural areas like Zavala and Jim Wells County reported transportation challenges as a factor influencing health compliance. As one participant noted, *"There is an agency that provides transportation to medical appointments but the service is very limited. I even heard that they'll leave patients behind if they are late because they are so busy."*
- **In Cameron County (Brownsville, TX):** Participants in the border regions of Webb County and the Rio Grande Valley also felt the effects of the suffering economy; underemployment, the stagnation of wages, and insufficient benefits were noted as the biggest barriers to economic mobility and negative health outcomes.
- **In Hidalgo County (San Juan, TX):** Colonia residents described limited access to healthcare services, therefore solely relying on mobile health clinics and community health workers to address their health concerns. Across all six focus groups, there was consensus that *"going to the people is the only way to get the word out about health."* In terms of accessing care, one *colonia* resident said that other mothers only trusted her when their children were sick because she had the most experience and access to medication. Other residents described giving their extra medication to friends and family members in times of need.

- **In Jim Wells County (Alice, TX):** For participants in the Coastal Bend area, the declining oil industry was described as particularly devastating to the local economy. As one participant described, "*The oil industry is cyclical…we are all riding really well until the town dries up and they go somewhere else*."

High Burden of Chronic Diseases and Risk Factors

*"We **lack a sense of consistency** around wellness in the community."–Focus group participant*

Apart from socioeconomic factors, focus group participants described a high burden of chronic diseases and their risk factors-- **mainly diabetes, cancer, and substance abuse** as significant concerns that impact many residents. In addition, mental health issues including **stress** and **anxiety** were frequently cited as challenges among participants.

Substance abuse was mentioned in every focus group, with participants concerned about a range of substances ranging from marijuana to opioids. Synthetic marijuana known as "K-2" was mentioned in three of the groups, in Nueces, Jim Wells, and Webb counties. Across geographies, participants strongly agreed that there was a **lack of substance abuse and recovery services** in their communities, noting: "*You don't see any detoxes around*."

Participants were particularly concerned **about co-occurring instances of mental health and substance abuse issues among youth**. In some instances, residents believed that providers were over prescribing/diagnosing issues like ADHD, and as a result, enabling addictive behavior: *"Doctors just give you a pill for your kids to make them robots because they don't want to give you the time of day. My kid didn't need medication; what he needed was the attention from his teacher and counselor."*

In regards to **preventive health**, focus group participants described **healthy eating** and **physical activity** as ways to stay healthy, but cited a **lack of health literacy** and **affordable recreational programming** in their communities. Among all focus groups, Hispanic culinary norms were attributed to poor health outcomes including diabetes, cardiovascular disease, and high cholesterol. As one resident noted, "*My whole family has diabetes…it's expected that we'll either be fat or diabetic because of the way we eat."*

Lastly, focus groups participants expressed concern over the lack of community resources around **sexual health, particularly for youth.** Teen pregnancy and sexually transmitted infections were perceived as especially concerning, with residents describing *"thirteen and fourteen year olds running around having kids,"* and the importance of *"communicating in the home."*

- **In Nueces County (Corpus Christi, TX):** Mental health was reported as a major concern among the homeless population, particularly stress, anxiety, and depression. Participants who were homeless described being denied mental health care because of their indigent status and said, *"If you're not suicidal they won't treat you and will send you to another hospital. But we need help too…a lot of us are stressed all the time."*
- **In Webb County (Laredo, TX):** Alcohol and drug abuse were linked to increased rates of domestic and community violence, with one participant noting that, "*The silence around drugs and mental health in our culture becomes especially problematic for our children who experience trauma from elementary school to adulthood.*"

- **In Zavala County (Crystal City, TX):** Rural cities in the Coastal Bend area described a lack of resources that encourage healthy lifestyles such as a YMCA or organized sports, and were especially concerned about how this would affect teens. Residents in Zavala County reminisced about a teen center that had closed several years before saying, "*I would do anything if my high school students had access to a resource like that again."*
- **In Cameron County (Brownsville, TX):** Residents in Cameron County reported the need for health literacy initiatives, citing the *Salud y Vida* program as an example. As one participant noted, "*I want to be taught how to eat right. We are lacking nutritional education, especially because now kids eat horrible food at school, and parents should know how to keep them healthy*."
- **In Hidalgo County (San Juan, TX):** *Colonia* residents in the border regions of the Rio Grande Valley and Laredo described barriers to accessing oral health in their communities. Many participants sought dental care across the border in Mexico. Undocumented citizens were described as the most at-risk for poor oral health: *"Many people can't cross over [the border] to see a dentist because of their status, and so they go untreated.*"
- **In Jim Wells County (Alice, TX):** Residents in the Coastal Bend area were especially concerned about the impact the oil industry was having on poor health outcomes, particularly cancer. As one resident said, *"I worked for the biggest refinery in town. I started feeling sick an hour after walking through the door."*

Difficulty Navigating a Complex Health System

> ***"I'm educated and I feel really dumb when it comes to navigating the healthcare system."***
> ***–Focus group participant***

Across several groups, many participants also described feeling "**dumb" when navigating the healthcare system,** saying: "*Everything is in acronyms. Terminology is a big problem…they might as well be speaking in Greek. I need to know what they are actually saying in layman's terms so I don't feel stupid*."

Programs such as *Salud y Vida* and nutrition classes at Mercy Ministries of Laredo were cited as valuable community resources addressing preventive health. Though, a majority of focus group participants reported that they **did not typically seek out preventive services**, citing that it was more a cultural norm to wait until things get very bad before seeking help. Across geographies, many focus group participants agreed that they **would not seek care for a general issue** such as the common cold or an ear infection. For more severe health problems, most participants sought care at **hospital emergency rooms** or **private urgent care clinics.**

Timeliness of care was a common concern across the six groups, with residents reporting long wait times and follow-ups. Further, some groups voiced frustration **over perceptions that undocumented citizens received care faster** than American citizens. As one resident noted, "*I pay my taxes and have all the required documents, and yet, I have to wait six months to see a doctor because people who are undocumented can walk right in*." Many participants reported **navigating long wait times by traveling to Mexico** for care, or attempting to treat ailments with **over the counter or home remedies**. As one participant described, "*I know if I try to go to the doctor I'll have to wait three or four months for an appointment, so it's better if I go to Wal-Mart, the Dollar Store, or Mexico and guess what medicine will make me feel better*."

In Webb County, residents described **routinely calling the ambulance for minor injuries** and illnesses to avoid wait times. Many noted the increase of urgent care clinics in the community, but were unaware of the differences in pay structures between for profit and nonprofit clinics. Insurance barriers were also attributed to the **over-utilization of emergency rooms**. As one participant noted, "*People go to the ER because they don't have insurance. When you go to the doctor you have to pay a co-pay, and for people who can't afford it, they'll go to the ER because they're not charged immediately."*

Many focus group participants reported **dissatisfaction in the coordination of care** in the communities, with the exception of Webb County. Residents in Webb County praised their care coordination and noted, "*Even amongst the agencies that exist here, they share resources, which you don't find that in a lot of other communities. Sometimes they keep information to themselves due to competition. But here, you don't see that competition; there is always a willingness to share resources to provide better services for those in need*." On the contrary, residents in the Coastal Bend area and Rio Grande Valley described their care as **fragmented and uncoordinated**. As one resident noted, "*Coordination doesn't exist in the Valley. You get referred to the doctor's buddy, and then the specialist sends you to get the exact same test done and no one explains why.*"

Focus group participants across all groups commented that they believed doctors were **over-medicating and over-testing residents**. Participants perceived that **doctors ordered unnecessary testing**, as one example from a participant: *"I got sent to a specialist and they ordered the exact same tests I took two days before*." Many residents thought money was the driving factor behind their concerns. As one participant noted, "*Doctors took an oath to care for the person, not to get rich off of their illnesses*." Further, there was a general **distrust around prescriptions and referral processes**. As one resident described, "*A lot of doctors have partnered with home health agencies and pharmaceutical companies.* ***Everything is the compadre system around here.*** *Their focus is on how much money they are going to make and what the perks will be when sending referrals*."

Further, residents stressed the importance of conveying sensitive health information from a **collaborative** perspective saying, "*Doctors tell you the brutal truth in a way that makes you want to run. If they put it in a different light and said 'we are a team and we can work to improve this together', it would make all the difference.*"

Very few focus group participants **were aware of new research studies or treatment options** in their communities. Residents who were aware of research studies were engaged with the local universities in some capacity, whether through employment or attending university-sponsored events. Of the few participants who had participated in clinical trials, none of them were told about the results of the study, which frustrated many.

- **In Nueces County (Corpus Christi, TX):** In Corpus Christi, focus group participants distrusted research studies and new treatment options due to belief that: "*They are targeted towards the poor because they offer money*." Many residents agreed and added: "*Is it me, or are they trying to get rid of us?"*
- **In Webb County (Laredo, TX):** In Webb County, residents described routinely calling the ambulance for minor injuries and illnesses to avoid wait times. Many noted the increase of urgent care clinics in the community, but were unaware of the differences in pay structures between for-profit and nonprofit clinics.

- **In Zavala County (Crystal City, TX):** Many focus group participants emphasized the importance of healthcare providers following up in a timely fashion. As one participant described, "*If I have a question I want to know that the doctor will get back to me. If a provider tells me that they are going to call me and they never do, even for just a 5-minute phone call, I lose trust*."
- **In Cameron County (Brownsville, TX):** In the Rio Grande Valley, residents wished to "*see more regulations for the monopolization of doctors and the healthcare system*," citing: "*If you go to one hospital they'll only send you to doctors they partner with instead of who is more accessible to you*."
- **In Hidalgo County (San Juan, TX):** Other participants suggested follow-ups as a way to encourage participation in new studies and treatment options saying, "*If doctors and nurses are wanting you to participate in something new, they could give you that information during your appointment and set something up so you can inform yourself and ask questions later."*
- **In Jim Wells County (Alice, TX):** In rural areas such as Alice, residents thought research studies and new treatment options were only available in bigger cities like San Antonio, and "*wished they would bring that stuff to the smaller cities*."

Residents Prefer a Mixed-Method Strategy for Receiving Health and Research Information

When asked how patients would like to receive health-related information and research findings, participants overwhelmingly agreed that a **mixed-method** communication strategy was important.

Many residents agreed that **face-to-face communication and word of mouth** were the preferred method of engaging patients in new treatment plans and research studies, saying "*I want to be able to look someone in the eye when they're telling me about this stuff because that's how I know I can trust them*." Many also described wanting to talk to people in the community who had participated in new studies or treatment options before making a decision.

The **internet** was the second most cited source to receive up-to-date medical information and research findings, with residents citing Facebook and email as the most popular ways to reach them However, many participants indicated that television was the least effective way to get information out, saying "*you always see them trying to sell medications to you on TV, then at the end they describe a million side effects that will happen to you if you participate*."

Community Health workers or *promotores* were seen as assets in communities, namely in the border regions of Laredo and the Rio Grande Valley. Residents in the upper Valley agreed that community health workers were effective, but stressed the importance of also **partnering with a local neighborhood champion** to conduct outreach with community health workers, saying, "*If promotoras worked with the leaders in the colonias they would have more success reaching residents who aren't engaged. They need to accompany the promotoras on their home visits, because many of us won't even open the door if we don't recognize the person knocking."*

The importance of **considering literacy levels** was also mentioned, with one resident saying, "*My parents only have a 4th grade education, and they often need me to reinterpret what the doctors are saying to them. When me or my brothers can't be there, I'd like them to have a written document that they can understand, something self-explanatory instead of using big words or medical terms.*" Many residents agreed, and added

that **family engagement was important** as well. As one resident described, *"Families need to be told this information too because many times we are the sole caregivers*."

- **In Nueces County (Corpus Christi, TX):** Residents in Corpus Christi reported face-to-face communication being the most effective way to disseminate health information. As one respondent said, "*The nurses you all send [Methodist Healthcare Ministries' Wesley nurses] will go under the bridge and tell us about resources we qualify for. I can tell they care about us [the homeless population*]."
- **In Webb County (Laredo, TX):** In Webb County, many patients spoke about relying on community health workers for new health information, saying: "*We trust community health workers because they're from the neighborhood, from the community, and they understand us."*
- **In Zavala and Wells County (Crystal City & Alice, TX):** Residents in more rural areas like Alice and Crystal City preferred flyers in public spaces, mail-outs, newsletters, and newspapers to disseminate information to the masses.
- **In Cameron County (Brownsville, TX):** In the lower Valley, residents suggested local radio stations and television networks such as KGBT 98.5.
- **In Hidalgo County (San Juan, TX):** In the upper Rio Grande Valley, participants wanted to receive this information from organizations they trusted such as *La Unión del Pueblo Entero (LUPE)* and *Proyecto Azteca*.

CONCLUSION

The focus groups conducted in **Advancing Health in South Texas Engagement Series: *What Matters to You?*** provide valuable insights to the unique strengths and challenges experienced by South Texas residents. Findings from this report are meant to serve as a foundation to guide discussions throughout the PCORI project with academic researchers, healthcare leadership, public health leadership, and other stakeholders, to create a framework that guides system alignment through authentic patient engagement in future dissemination strategies. More importantly, it highlights commonalities across municipalities that can be leveraged to actively involve South Texas residents in co-constructing solutions to the health challenges experienced in the region.

"If we all worked together we could make positive changes in our lives and communities." –Focus group participant

APPENDIX

Health Resources in Action
MHM PCORI Engagement Series
Community Focus Group Guide

Goals of the focus groups:

- To gain an understanding of people's experiences with and barriers to accessing health care services in the community
- To identify people's communication with their health care providers and ways of receiving health information
- To identify strategies for engaging community members in research findings and dissemination

[NOTE: THE QUESTIONS IN THE FOCUS GROUP GUIDE ARE INTENDED TO SERVE AS A GUIDE, BUT NOT A SCRIPT.]

I. BACKGROUND (5-10 MINUTES)

- Welcome everyone. My name is _____, and I work for Health Resources in Action, a non-profit public health organization in Boston.
- We're going to be having a focus group today. Has anyone here been part of a focus group before? You are here because we want to hear your opinions. I want everyone to know there are no right or wrong answers during our discussion. We want to know your opinions, and those opinions might differ. This is fine. Please feel free to share your opinions, both positive and negative.
- Methodist Healthcare Ministries is conducting a series of discussions to better understand the health issues facing South Texas residents, how these needs are currently being addressed, and opportunities to improve health-related communication and research findings in the community. We are funded by the Patient-Centered Outcomes Research Institute (PCORI). PCORI's goal is to help people make better health care decisions by having a say in the research that affects their health. PCORI's goal is different than most organizations that give money for research. PCORI wants [you/people] to have a say in what research studies should focus on so that future research can answer the questions that are most important to [you/them].
- As you can see, I have a colleague with me today, [NAME], who is taking notes during our discussion. She works with me on this project. I want to give you my full attention, so she is helping me out by taking notes during the group and she doesn't want to distract from our discussion.
- [NOTE AUDIOTAPING IF APPLICABLE] Just in case we miss something in our note-taking, we are also audio-taping the groups tonight. We are conducting several of these discussion groups around Texas, and we want to make sure we capture everyone's opinions. After all of the groups are done, we will be writing a summary report of the general opinions that have come up. In that report, I might provide some general information on what we discussed tonight, but I will not include any names or identifying information. Your responses will be strictly confidential. In our report, nothing you say here will be connected to your name.
- You might also notice that I have a stack of papers here. I have a lot of questions that I'd like to ask you tonight. I want to let you know that so if it seems like I cut a conversation a little short to move on to the next question, please don't be offended. I just want to make sure we cover a number of different topics during our discussion tonight.

- Lastly, please turn off your cell phones or at least put them on vibrate mode. The group will last only about 80-90 minutes. If you need to go to the restroom during the discussion, please feel free to leave, but we'd appreciate it if you would go one at a time.
- Any questions before we begin our introductions and discussion?

II. INTRODUCTION AND WARM-UP (5-10 MINUTES)

1. Now, first let's spend a little time getting to know one another. Let's go around the table and introduce ourselves. Please tell me: 1) Your first name; 2) what community you live in; and 3) something about yourself – such as how many children you have or what activities you like to do in your spare time. [AFTER ALL PARTICIPANTS INTRODUCE THEMSELVES, MODERATOR TO ANSWER INTRO QUESTIONS]

III. COMMUNITY AND HEALTH PERCEPTIONS (10 MINUTES)

2. Today, we're going to be talking a lot about the community that you live in. How would you describe your community?

3. If someone was thinking about moving into your community, what would you say are some of its biggest strengths or the most positive things about it? [PROBE ON COMMUNITY AND ORGANIZATIONAL ASSETS/STRENGTHS]

    a. What are some of the biggest problems or concerns in your community? [PROBE ON ISSUES IF NEEDED – HEALTH, ECONOMIC, SOCIAL, SAFETY, ETC.]

4. What do you think are the most pressing *health* concerns in your community?

    b. How have these health issues affected your community? In what way?
    c. What specific population groups are most at-risk for these issues?

5. What are some factors that make it easier to be healthy in your community?
6. What are some factors that make it harder to be healthy in your community?

IV. DECISION MAKING AND ACCESS TO HEALTH CARE SERVICES (40 MINUTES)

7. I'd like to ask specifically about health care in your community. What do you think about the health care services in your community? [PROBE – perceptions of quality, accessibility, etc.]

8. Have you or someone close to you ever experienced any challenges in trying to get health care? What specifically? [PROBE FOR BARRIERS: INSURANCE ISSUES, LANGUAGE BARRIERS, LACK OF TRANSPORTION, ETC.]

9. For your own personal health care - if you or your family had a general health issue that needed a doctor's care or prescription medicine – such as the flu or a child's ear infection– where would you go for this type of health care? [PROBE IF THEY GO TO PRIVATE PRACTICE, ED, ETC]

10. What about if you had a more urgent health problem that needed a doctor's care – such as a serious illness or injury – where would you go for this type of health care? Why? [PROBE FOR SPECIFIC INSTITUTIONS]

    a. How do you decide where to go for care? What things do you consider when making the decision of who to go to for routine care? How about for more urgent or serious care?

    b. Do you have someone that you consider your own personal health care provider (doctor, nurse practitioner)?

[IF YES to 10b.]

i. Do you see this same person each time?

ii. What type of setting does this person work in – a clinic, hospital, private practice, etc?

iii. How did you pick this person?

iv. What do you think this person's interaction is with any other providers you see?

1. How much do you think your care is coordinated among the providers you see?

[IF NO to 10b.]

i. Why not? What has made it hard to be able to see the same person each time you need health care?

c. How would you describe your relationship with your healthcare providers?

d. How comfortable do you feel asking your provider questions?

i. What makes it hard to ask questions to your provider about your health or health care?

ii. What makes it easier to ask him/her questions?

e. How much do you feel that your health care providers give you the most up-to-date information about your health?

i. What makes you say that? Are there specific examples you can provide?

ii. When you provider gives you health information, does he/she talk about where it's from? (e.g., a new study, their colleagues, etc.)

iii. Is there anything you would like to change about your relationship with your health care provider(s) or how you talk to each other? What specifically?

V. ENGAGING PATIENTS/DISSEMINATING HEALTH INFORMATION (30 MINUTES)

f. How do you currently find out about new health findings or treatment options? (Doctors, nurses, community leaders, community health workers, peers, family, etc.)?

i. From what source do you prefer to receive this type of health information?
    1. Why? What about that source do you find appealing?
ii. Who do you trust most to give you information about health and treatment options?
    1. Why? What about that source is trustworthy?

11. If an organization in the community wanted to provide more information about new health findings, what is the best way to communicate it to you and your friends or family? [PROBE SPECIFICALLY ON COMMUNICATION CHANNELS: TV (what language?), newspaper (which ones?), magazines, through community leaders (examples), through churches or other organizations, online]

12. There are hospitals, healthcare providers, and universities in the region that conduct studies to test new treatments and options of care. Have you heard about any studies in your community? Which ones?
    a. If your doctor asked you or your family to be part of a new study for a health issue you have, what would you want to know? What questions would you have?
        i. In what way would you want to receive this information (Written, oral)?
    b. What is the best way for people to understand what the study is about so that they can decide whether or not to participate?
        i. Why might people want to participate in a study or new treatment option?

13. How can healthcare providers help patients understand why being part of a study might be helpful to them?
    a. How can healthcare providers help patients understand what might be the risks – or potential problems – of being part of a research study?
    b. There are lots of studies going on in the health world. What is the best way to communicate the results of these studies?
        i. What would you want to know about the results of the study?
        ii. How can a provider or someone else talk about these studies so they can help you make decisions about your health?
        i. What are some of the things you would want to know?
        ii. How would you decide whether or not to make changes about your health because of these results?

VI. CLOSING (5 MINUTES)

Thank you so much for your time and sharing your opinions. Before we end the discussion, is there anything that you wanted to add that you didn't get a chance to bring up earlier?

I want to thank you again for your time. And we'd like to express our thanks to you. [DISTRIBUTE STIPENDS AND HAVE RECEIPT FORMS SIGNED]

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