



# From Infant Mortality to Infant Vitality:

Qualitative and Quantitative Evidence Among  
Hispanics in Elkhart County, Indiana  
**2025**



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Qualitative and Quantitative Evidence Among Hispanics  
in Elkhart County, Indiana

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## ABSTRACT

Infant mortality rates are above state and national levels among the Hispanic community in Elkhart County, Indiana. The Northern Indiana Hispanic Health Coalition (NIHHC) aims to design and deliver an infant mortality prevention communications campaign with a goal of reducing infant mortality in vulnerable areas of the county (zip codes 46514, 46516, 46517) by addressing and ameliorating modifiable risk factors. This study explores the qualitative and quantitative data to explore the context of perinatal health and infant mortality and more deeply understand the drivers behind poor birth outcomes among the Hispanic origin population of Elkhart County, Indiana.

We collected qualitative data among the Hispanic population and providers who serve them to develop a conceptual model of perinatal health and infant mortality. We conducted four small group interviews with healthcare providers and social service experts in Elkhart County (N=25). We also conducted five focus groups with Hispanic men and women who have recently had a baby or engaged with the healthcare system in the prenatal or postpartum period in Elkhart County (N=30). Based on this data, we gained insight into the knowledge they have of perinatal health and their perception of the causes and contributors to infant mortality. We also gained a more comprehensive view of why healthcare and social services are not utilized or are underutilized, and what can be done about it. We conclude the report by mapping these findings onto the socio-ecological model to help stakeholders identify where they can effect change.

We collected quantitative data to explore community perceptions of infant mortality and related services for perinatal health. We also explored their preferred communication channels for dissemination of a prevention campaign. Through a community demographic (N=511) and infant mortality survey (N=511), emerging community priorities include prenatal care, nutrition, health insurance/Medicaid access, and stable housing.

## INTRODUCTION

### BACKGROUND

Infant mortality is the death of an infant before their first birthday. The infant mortality rate is an important marker of the overall health of a society. In 2022 in the United States, 20,577 infants died from causes like preterm birth, low birth weight, and sudden infant death syndrome, a 3% increase from 2021 (Ely & Driscoll, 2024). In 2022 in Indiana, 577 infants died before their first birthday (Indiana Department of Health, 2023). Although the rate of infant deaths has fallen over the past decade, there are disparities by race/ethnicity, income, and geographic location. A clear example is the increase in infant mortality among Hispanics in Indiana, especially in zip codes 46514 and 46416 in Elkhart County. Equitable, high-quality care for moms and babies and community-based interventions can help reduce the rate of infant deaths.

As described by March of Dimes (2024a), the leading causes of infant mortality in Indiana are birth defects (22%), pre-term low birth weight (14.4%), SIDS (9.1%), and accidents (7.6%). Pre-term birth is flagged as a leading cause of infant mortality in all the national and state-level data reports. The March of Dimes (2024a, 2024b) also highlights the chronic conditions making people in Indiana more likely to have pre-term birth, such as smoking, hypertension, unhealthy weight, and diabetes, as well as the impact of factors, such as the physical environment and inadequate access to prenatal care, on adverse birth outcomes.

Indiana ranks 40th in the nation (11<sup>th</sup> highest) for infant mortality rates (United Health Foundation, 2023). Hispanic children in Indiana bear a disproportionate burden of risk. The number of Hispanic children in Indiana in 2021 who died before age one (8.1 infant deaths per 1,000 live births) is significantly higher than the state rate (6.7), national rate (5.4), and the Healthy People 2030 target (5.0) (Indiana Department of Health, 2023a; U.S. Department of Health and Human Services, 2023). Elkhart County ranks among the top ten highest infant mortality rates in Indiana at 8.2 and has the highest county-level rate for Hispanics at 8.3 (2023a). This rate is disproportionately high compared to non-Hispanic Whites (6.5) in Elkhart County (Indiana Department of Health, 2023b). Further, the highest infant mortality rates in the state by zip code are in Elkhart County, at 13.7 in 46516 (1<sup>st</sup> highest) and 10.8 in 46514 (6<sup>th</sup> highest), both in the city of Elkhart (2023a). In 46514, the infant mortality rate is also disproportionately high for Hispanics at 12.3 compared to 9.0 for non-Hispanic Whites (2023). Elkhart County rates are strikingly high when compared with 2024 data from developing countries such as Peru (10.8), Colombia (11.7), or even Mexico (12.1) (Central Intelligence Agency, 2025). The high rates in Elkhart County reveal the need in the Hispanic community for increased education on the prevention of infant mortality. They also suggest the need among providers to serve and implement health initiatives in a manner that is culturally appropriate and responsive to individuals' social drivers of health and lived realities.

### STUDY AIMS AND GOALS

Using qualitative and quantitative methods, we aimed to understand the context of infant mortality and perinatal health among the Hispanic population in northern Indiana and to understand the drivers of poor birth outcomes.

**Aim #1:** to develop a conceptual model of perinatal health and infant mortality;

**Aim #2:** to explore community perceptions of infant mortality and related services for perinatal health

Our primary goal was to design and implement an effective communication campaign to improve perinatal health and address the needs identified through qualitative and quantitative data collection. Our secondary goal was to create a set of communication, educational, and/or programmatic recommendations that can inform and support best practices across the socio-ecological model for improved birth outcomes for the Hispanic population in northern Indiana.

### METHODS

#### STUDY DESIGN

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##### QUALITATIVE

A qualitative approach was used to collect and analyze data.

Qualitative methods included focus groups and small group interviews. Analysis of this data was based on a constructed grounded theory approach (Charmaz, 2006) to explore 1) healthcare providers' experiences working with the Hispanic population seeking prenatal and postpartum care and what they believe about barriers to services and other needs and gaps that exist; and 2) experiences of Hispanic men and women who have recently had a baby or engaged with the healthcare system for prenatal or postpartum care in Elkhart County and their awareness, knowledge, and attitudes toward perinatal health and perceived barriers to care. All research materials were offered in both English and Spanish.

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##### QUANTITATIVE

A quantitative approach was also used to collect and analyze data.

Quantitative methods included administering two surveys with closed responses. A demographic survey asked participants at NIHHC health-related events to share their demographic characteristics, and an infant mortality survey asked the same participants about their understanding of the causes of infant mortality in Elkhart County and their assessment of the medical and social services needed before, during, and after pregnancy. Both cross-sectional surveys were employed with a convenience sample of Hispanic men and women living

and working in Elkhart County. Both the demographic and infant mortality surveys were available in English and Spanish.

SAMPLE

QUALITATIVE

Participants for the qualitative study were recruited through healthcare centers that provide some level of prenatal care in Elkhart County. First, we contacted the prenatal care coordinators at each center and invited them to be part of the small group interviews. During those interviews, we invited the centers to participate in focus groups with their clients who regularly attend meetings at their centers or who frequent their centers for regular services, such as shopping at the Babe Store. Second, we shared recruitment flyers at those healthcare centers and invited clients to sign up to be part of this research opportunity. Individuals were eligible to participate in the qualitative study if they were aged 18 years or older, or if they were parents, expectant parents, or of reproductive age; spoke Spanish; and identified as Hispanic, Latino, or Latinx. Bilingual research team members were available for all participant interactions. Participants completed a brief demographic questionnaire.

We conducted four group interviews among healthcare and social service providers (Table 1). We conducted an additional five focus groups with Hispanic men and women who have recently had a baby or have experience in the healthcare system seeking prenatal or postpartum care in Elkhart County (Table 2).

**Table 1.** *Demographic characteristics of participants in small group interviews as reported in the demographic questionnaire*

<b>Group Interview Participant Characteristics</b>	<b>Total (n= 25)</b>
<b>Gender identity, n (%)</b>	
Women	25 (100)
Men	0 (0)
<b>Race or ethnicity (check all that apply), n (%)</b>	
Hispanic or of Spanish origin	8 <sup>a</sup> (100)
Non-Hispanic origin	17
<b>Birthplace, n (%)</b>	
Outside the United States	5 (100)
United States	20 (0)
<b>Educational attainment, n (%)</b>	
High school graduate or GED <sup>c</sup>	4 (16)
Some college	7 (28)
RN	8 (32)
Other college graduate	6 (24)

Participant distribution (n=25): RETA Pregnancy Clinic & Family Resources (2), Maple City Health Care Center (2), Elkhart County Health Department–Healthy Babies (5), Women’s Care Center (13), Other: Social Service Provider (1), Medical Interpreter (1), Nurse (1)

**Table 2.** Demographic characteristics of participants in focus groups as reported in the demographic questionnaire

Focus Group Participant Characteristics	Women’s Care Center 2 events (n=11)	RETA 1 event (n=9)	WIC 2 events (n=10)	Total (n=30)
<b>Age (y), mean (SD)</b>	32 (5)	32 (6)	31 (8)	32 (6)
<b>Gender identity, n (%)</b>				
Women	11 (100)	8 (89)	7 (70)	26 (87)
Men	0 (0)	1 (11)	3 (30)	4 (13)
<b>Race or ethnicity (check all that apply), n (%)</b>				
Hispanic or of Spanish origin	11 <sup>a</sup> (100)	9 (100)	10 (100)	30 (100)
<b>Birthplace, n (%)</b>				
Outside the United States <sup>b</sup>	11 (100)	9 (100)	9 (90)	29 (97)
United States	0 (0)	0 (0)	1 (10)	1 (3)
<b>Educational attainment, n (%)</b>				
Elementary school or lower	0 (0)	1 (11)	0 (0)	1 (3)
Some high school	7 (64)	3 (33)	4 (40)	14 (47)
High school graduate or GED <sup>c</sup>	0 (0)	1 (11)	4 (40)	5 (17)
Some college	2 (18)	1 (11)	1 (10)	4 (13)
College graduate	2 (18)	3 (33)	1 (10)	6 (20)
<b>Health insurance (check all that apply), n (%)</b>				
Employer-sponsored	1 (9)	2 (22)	1 (10)	4 (13)
Medicaid	7 <sup>a</sup> (64)	3 (33)	1 (10)	11 <sup>a</sup> (37)
None	1 (9)	4 (44)	2 (20)	7 (23)
Emergency Medicaid	1 (9)	0 (0)	5 (50)	6 (20)
Marketplace	1 (9)	0 (0)	1 (10)	2 (7)
<b>Employment, n (%)</b>				
Homemaker	4 (36)	2 (22)	5 (50)	11 (37)
Employed	5 (45)	5 (56)	2 (20)	12 (40)
Unemployed	2 (18)	2 (22)	2 (20)	6 (20)
Prefer not to answer	0 (0)	0 (0)	1 (10)	1 (3)

Focus Group Participant Characteristics	Women's Care Center 2 events (n=11)	RETA 1 event (n=9)	WIC 2 events (n=10)	Total (n=30)
<b>Have you been diagnosed with Diabetes, Obesity, Depression, ...? (check all that apply), n (%)</b>				
Diabetes	1 (9)	1 (10)	2 <sup>a</sup> (20)	4 <sup>a</sup> (13)
Obesity	0 (0)	2 (20)	0 (0)	2 <sup>a</sup> (6)
Depression	0 (0)	1 (10)	0 (0)	1 (3)
Other: high cholesterol	2 (18)	0 (0)	3 (30)	5 (16)
High-risk pregnancy	1 (9)	0 (0)	0 (0)	1 (3)
None	7 (64)	6 (60)	2 (20)	15 (48)
Prefer not to answer	0 (0)	0 (0)	3 (30)	3 (10)
<b>Transportation, n (%)</b>				
Drive a car regularly	8 (73)	4 (44)	8 (80)	20 (67)
Don't drive a car	3 (27)	2 (22)	2 (20)	7 (23)
Prefer not to answer	0 (0)	3 (33)	0 (0)	3 (10)
<b>Marital Status, n (%)</b>				
Single	3 (27)	3 (33)	6 (60)	12 (40)
Married	8 (73)	6 (67)	3 (30)	17 (57)
Prefer not to answer	0 (0)	0 (0)	1 (10)	1 (3)
<b>Barriers to having access to healthcare in the Elkhart Co. area (check all that apply), n (%)</b>				
Language	9 <sup>a</sup> (33)	6 <sup>a</sup> (25)	4 <sup>a</sup> (21)	19 <sup>a</sup> (27)
Racism / Discrimination	0 (0)	5 <sup>a</sup> (21)	0 (0)	5 <sup>a</sup> (7)
Cost	10 <sup>a</sup> (37)	5 <sup>a</sup> (21)	6 <sup>a</sup> (32)	21 <sup>a</sup> (30)
Transportation	2 <sup>a</sup> (7)	2 <sup>a</sup> (8)	4 <sup>a</sup> (21)	8 <sup>a</sup> (11)
Lack of Health Insurance	3 <sup>a</sup> (11)	4 <sup>a</sup> (17)	4 <sup>a</sup> (21)	11 <sup>a</sup> (16)
Don't understand how the health system works	3 <sup>a</sup> (11)	2 <sup>a</sup> (8)	1 <sup>a</sup> (5)	6 <sup>a</sup> (9)
<b>Living Status, n (%)</b>				
Live with my partner	5 (45)	4 (44)	9 (90)	18 (60)
Live with family members	6 (55)	4 (44)	1 (10)	11 (37)
Prefer not to answer	0 (0)	1 (11)	0 (0)	1 (3)
<b>Prenatal care during pregnancy, n (%)</b>				
Y	9 (82)	5 (56)	8 (80)	22 (73)
N	1 (9)	2 (22)	0 (0)	3 (10)
Prefer not to answer	1 (9)	2 (22)	2 (20)	5 (17)
<b>Breastfeeding, n (%)</b>				
Yes	6 (55)	9 (100)	9 (90)	24 (80)
No	3 (27)	0 (0)	0 (0)	3 (10)
Prefer not to answer	2 (18)	0 (0)	1 (10)	3 (10)

Focus Group Participant Characteristics	Women’s Care Center 2 events (n=11)	RETA 1 event (n=9)	WIC 2 events (n=10)	Total (n=30)
<b>Language of preference at home, n (%)</b>				
English	0 (0)	2 (22)	0 (0)	2 (7)
Spanish	8 (73)	1 (11)	6 (60)	15 (50)
More Spanish than English	3 (27)	6 (67)	1 (10)	10 (33)
More English than Spanish	0 (0)	0 (0)	0 (0)	0 (0)
Both equally	0 (0)	0 (0)	3 (30)	3 (10)

<sup>a</sup>At least one participant selected this category and at least one additional category on a question with a “Mark all that apply” instruction.

<sup>b</sup>Participants (n=30) indicated the following countries of origin: Mexico (n=13, 43%), United States (n=1, 3%), Ecuador (n=1, 3%), Nicaragua (n=3, 10%), Honduras (n=8, 27%), and Venezuela (n=4, 13%).

<sup>c</sup>GED = General Educational Development test

## QUANTITATIVE

Participants for the quantitative study were recruited at NIHHC’s health-related events. These events had a significant representation of Elkhart County factory workers. During registration, participants were invited to fill out a survey. It took an average of 10 additional minutes of their time to complete it, which generally happened while they were waiting in line to receive their services. All interested individuals were assessed for eligibility in person by NIHHC staff. Individuals were eligible to participate in the survey if they were aged 18 years or older, or if they were parents, expectant parents, or of reproductive age; and spoke Spanish or English. Bilingual research team members were available for all participant interactions.

From June to December 2024, NIHHC asked a convenience sample of community members to complete the two surveys described above at 31 community events (see Appendix G). A total of 511 adults and youth under the age of 18 took part in the demographic and infant mortality surveys. Respondents included 434 adults over the age of 18 and 17 youth under the age of 18 (60 preferred not to answer regarding age). Just over 90% (91%; N=467) of survey respondents self-identified as Hispanic; 60% (N= 308) were female. Just over 80% (82%; N=422) had a Spanish language preference.

## DATA COLLECTION PROCEDURES

### QUALITATIVE

Healthcare professionals from the NIHHC research team, led by the principal investigator (PI), facilitated the focus groups and interviews over a series of days from January to September 2024. Data collection was conducted in person. The PI worked with local contacts to determine

the dates for data collection. The focus groups and interviews were held on a scheduled day and time and conducted in a relatively private space (i.e. some were conducted in a café but in a somewhat private area). Prior to starting the focus group or interview, we obtained verbal consent to record the session, assured individuals of confidentiality, and indicated the focus group or interview would last approximately 45 to 60 minutes.

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### QUANTITATIVE

Trained NIHHC staff conducted in-person demographic and infant mortality surveys in paper format from June to December 2024. Data collection took place during NIHHC's health-related events such as health fairs, flu shot clinics, and outreach activities.

Upon providing verbal consent, participants completed each survey in their preferred language. Data were collected by bilingual surveyors trained in the survey content and cultural competency by NIHHC.

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### ETHICAL CONSIDERATIONS

All subjects in the focus groups and interviews voluntarily participated. They were given explanations about the study, the participation format, and the confidentiality protocol; each of them provided verbal consent to be recorded. All transcripts were deidentified before analysis, and only deidentified quotes were reported. Focus group and interview participants received a gas gift card following participation.

All survey participants voluntarily completed the surveys. They were given explanations about the study and the participation format; each of them provided verbal consent to complete the surveys. No identifying information was collected, and no money or other incentives were offered to survey participants.

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### INSTRUMENTS

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#### QUALITATIVE

The interview guide for the healthcare providers initially consisted of 13 questions (plus additional prompts) designed to elicit information on experiences working with the Hispanic population seeking prenatal and postpartum care and what they believe about barriers to services and other needs and gaps that exist. After the first two interviews had been conducted and analyzed, two members of the qualitative research team reviewed the results and proposed an additional set of 8 questions to be asked in the remaining interviews with healthcare providers to gather deeper information on important ideas. (See Appendix A.)

The focus group guide for the Hispanic men and women consisted of 14 questions (plus additional prompts) designed to assess experiences of Hispanic men and women who have recently had a baby or engaged with the healthcare system for prenatal or postpartum care in Elkhart County and their awareness, knowledge, attitudes toward perinatal health and perceived

barriers to care. (See Appendix B.) Participants in the focus groups also completed a demographic survey, including 18 questions plus 10 sub-questions specifically on pregnancy and birth (see Appendix C).

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### QUANTITATIVE

All study participants completed a demographic survey (N=511), which included 9 items (see Appendix D). In addition to completing the demographic survey, community members attending NIHHC events were also asked (at the same location) to complete a cross-sectional survey on infant mortality (N=511). The infant mortality survey, informed by the literature, included 79 items adapted from previous studies (see Appendix E). The survey assessed eight subthemes: (1) health literacy insights; (2) knowledge and perceptions of research-identified causes of infant mortality in Elkhart County; (3) knowledge of available health services; (4) social drivers of health impacting pregnancy and baby; (5) satisfaction with health services used in Elkhart County; (6) health behaviors impacting healthy pregnancy and baby; (7) information and services needed; and (8) communication channels.

### ANALYSIS

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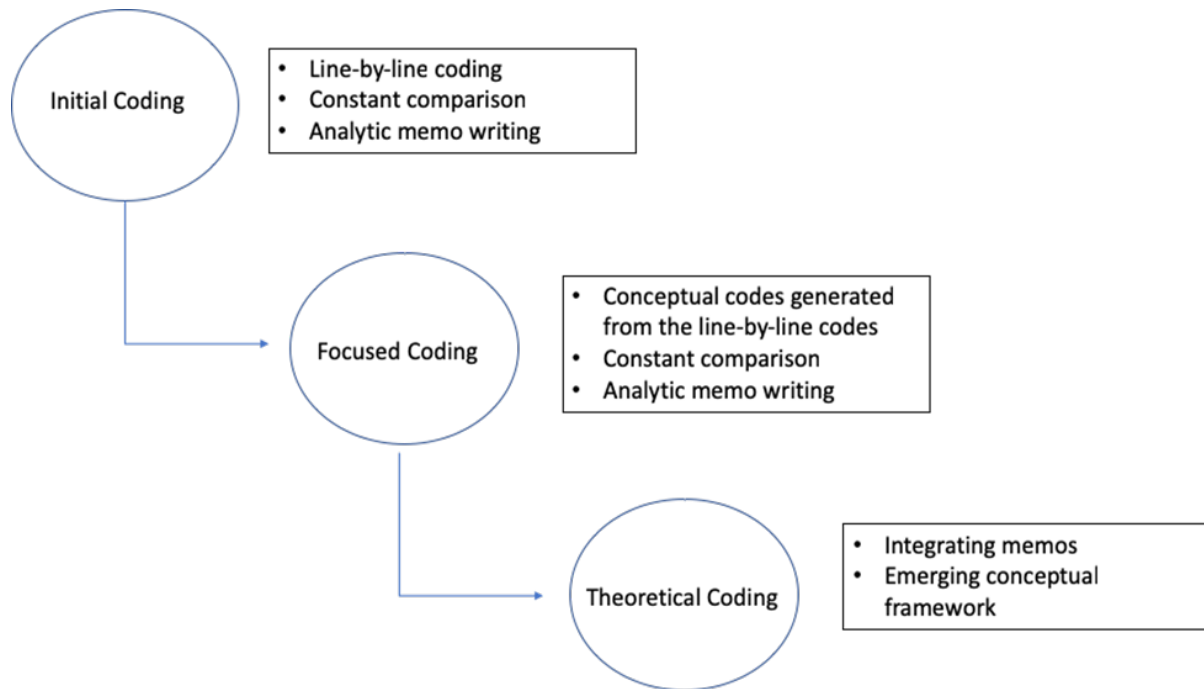
#### QUALITATIVE

Focus groups and interviews were recorded with verbal informed consent. They were transcribed in-house by research team members and staff at NIHHC and uploaded to the qualitative software NVivo 12. Members of the research team went through a training on qualitative coding. Following the training, they were assigned transcripts to code, following the process of first-level and second-level coding. In first-level coding, they read each assigned transcript line-by-line and broke down sentences or paragraphs looking for unique ideas that the participants were communicating. In second-level analysis, they grouped similar codes to coalesce and merge compatible ideas. To conclude, they looked for overall patterns and created summaries of ideas to communicate overarching themes across healthcare providers or Hispanic community members, respectively.

In some cases, members of the research team analyzed the same transcripts as a test of reliability of the coding. Second level codes were reviewed and compared for how similar and different they were. In the transcripts that were coded multiple times by different members of the team, the codes were determined to be consistent, thus enhancing the reliability of the analytic results. (See examples of line-by-line coding in Appendix F.)

After the first and second level coding was complete, the qualitative research lead combined all summaries to provide a concise list of results that include summary statements, relevant details, and exemplar quotes. Figure 1 illustrates the qualitative data analysis process.

Figure 1. Depiction of the data analysis process of the qualitative data



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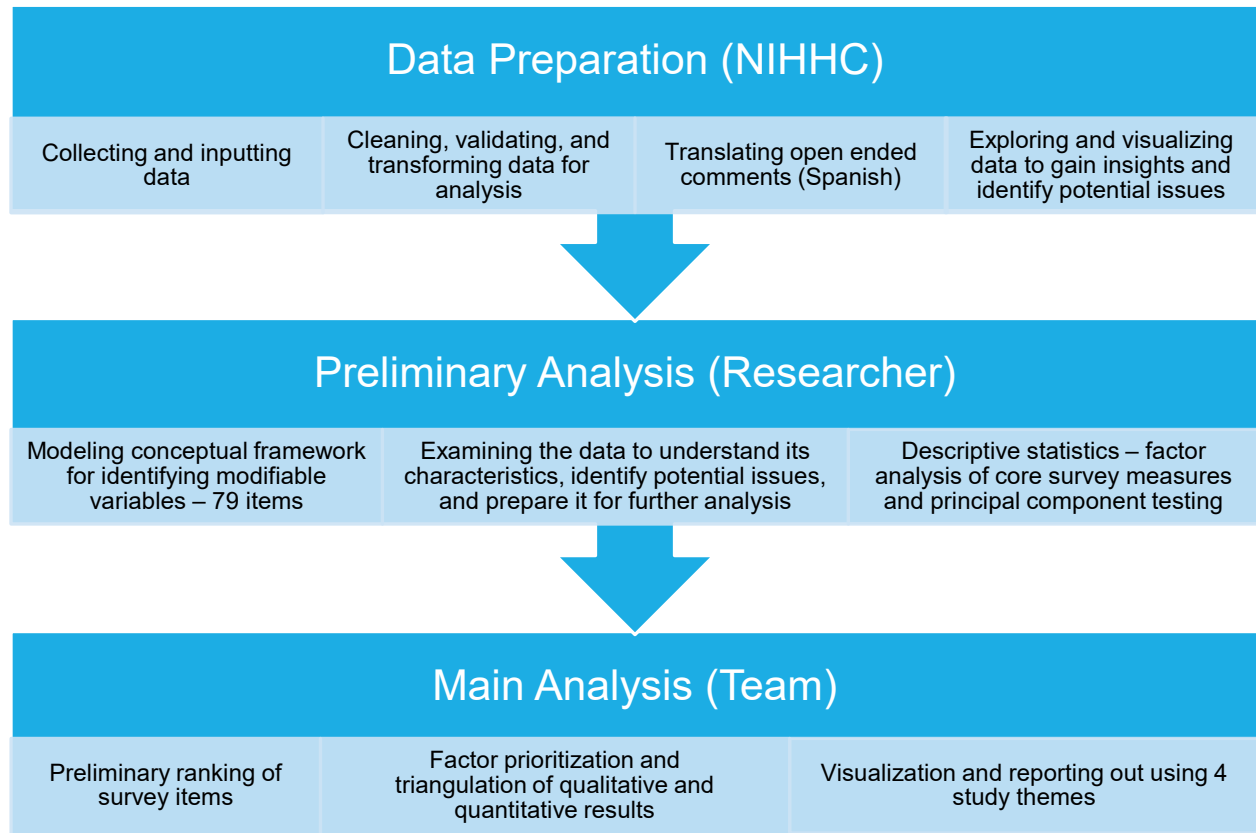
## QUANTITATIVE

Survey data was cleaned and validated by the quantitative research lead for preliminary analysis. Following a process of triangulation of quantitative and qualitative data, eight subthemes were verified and reported under four shared study themes (see Table 4, p. 33).

Quantitative data were analyzed in the statistical software, STATA version 18 using a  $p < 0.05$  to determine significance. Descriptive statistics (summarizing data into meaningful metrics like mean, median, and mode) were used to visualize priority items and identify areas for focus. Principal component testing of the nine Demographic Survey items using Pearson's chi-square ( $\chi^2$ ) and Fisher's exact tests revealed a significant association between race/ethnicity and gender/language preference, indicating these variables are not independent.

After the preliminary analysis was completed, the team triangulated qualitative and quantitative data. Community rankings of factors were sorted based on the average rank of each item by question. Results were reported out under four shared study themes: (1) Community Characteristics, (2) Awareness, Knowledge, and Attitudes towards Perinatal Health, (3) Barriers to Accessing Services, and (4) Needs and Gaps. A list of shared study themes, variables, and their descriptions and statistical measurement is presented in Table 4, p. 33. Figure 2 illustrates the quantitative data analysis process.

Figure 2. Depiction of the data analysis process of the quantitative data



## RESULTS

### QUALITATIVE

The theoretical themes relevant to the issue of infant mortality were identified through the lens of qualitative analysis, based on the experiences, perspectives, and perceptions of interview and focus group participants. Table 3 summarizes these themes, which helps to develop a conceptual model of perinatal health among Hispanics and aids in our understanding of the drivers of poor birth outcomes.

**Table 3.** Summary of theoretical themes based on responses from small group interviews and focus groups

Study Themes	Subtheme(s) Reported
Awareness, Knowledge, and Attitudes Towards Perinatal Health	<ul style="list-style-type: none"> <li>• Awareness-Raising is Important</li> <li>• Physical Health of the Mother Matters</li> <li>• Emotional Status of Parents Matters</li> <li>• Postpartum Period is Emphasized</li> <li>• Confusion About Safe Sleep</li> </ul>
Barriers to Accessing Services	<ul style="list-style-type: none"> <li>• Lack of Providers</li> <li>• Language and Cultural Barriers in Healthcare</li> <li>• Difficulties Understanding How the U.S. Healthcare System Functions</li> <li>• Low Health Literacy</li> <li>• Fear Associated with Immigrant Status</li> <li>• Fear of Judgment</li> <li>• High Cost</li> <li>• Lack of Support Systems for Childcare and Transportation</li> </ul>
Needs and Gaps	<ul style="list-style-type: none"> <li>• Lack of Culturally Competent, Spanish-Language Health Education</li> <li>• Inadequate Housing / Sleeping Situations</li> <li>• Financial Insecurity</li> </ul>

## THEMES IN AWARENESS, KNOWLEDGE, AND ATTITUDES TOWARDS PERINATAL HEALTH

We identified the following five subthemes. Quotes are sourced from transcripts from the community focus groups and small group interviews among providers.

### AWARENESS-RAISING IS IMPORTANT

Men and women initially demonstrate a lack of knowledge on infant mortality, but once they understand the definition, they recognize infant mortality as an important issue in their community. Based on their response to question #1 (see Appendix B), 90% of the focus group participants did not know the definition of infant mortality. Men and women encourage elevating the discussion on infant mortality among members of the Hispanic community because they believe it has the potential to change behaviors. Many individuals reported knowing someone who has lost a baby but noted the taboo of discussing the traumatic incident. Providers agree that infant mortality is an important issue in their community; however, they emphasize that providing education related to pregnancy and infant care among clients is more important than raising awareness about infant mortality. Community members focus more on how and whether explanation is provided, and the effectiveness of that explanation.

*“I think that while the process is going on, in a place like this or in a clinic, there should be information on mortality. Because for me, actually, that word—it’s new to me. I recently looked at it and I read it and I didn’t understand it. Mortality. It sounds like death, doesn’t it? So, I think there is a little bit of information missing.”*

*– Spanish-speaking community member; translated*

*“I don’t believe that Elkhart County has one of the highest rates of infant mortality in Indiana for Hispanics. Hispanics take good care of their children. However, among the Hispanic community, there are so many single moms, and taking care of a baby makes you tired. It is too much for just one person.”*

*– Spanish-speaking community member; translated*

*“We all have part ignorance, but if you don’t explain [it] to us, if you don’t let us know what it really is, if you don’t give us those resources, if you aren’t there to explain [it] to us, how do we know it? Okay, how does that saying go, ignorance ends when education is present. That’s the way it goes.”*

*– Spanish-speaking community member; translated*

*“There are a lot of things that we are watching on social media, TikToks, and so on. Maybe there are people who could help make [the information] a little bit attractive so that we don’t say, ‘oh, it’s another sheet’—I mean, ‘the questionnaire with a thousand questions’ or ‘the super long information that I don’t want to read’ or something like that. Maybe there are people who can make an explanatory, simple, eye-catching video, and that could be a little more attractive.”*

*– Spanish-speaking community member; translated*

*“...to see the numbers that you have presented [infant mortality rates in Elkhart Co. and in zip codes 46514 and 46516, like, that feels alarming to me. I would say, yes, I agree it’s a high priority. It does not feel like adequate care is being done if, in 2024, we’re seeing this many numbers of, yeah, of infant death.”*

*– English-speaking healthcare (medical) provider*

## PHYSICAL HEALTH OF THE MOTHER MATTERS

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When asked as a prompt among community members, maternal age and weight are perceived to play predominant roles in the causes of poor birth outcomes, but women and men lack the knowledge, self-efficacy and health literacy to know what to do with this information or how to ameliorate these risks. Overall, a mother’s health condition is recognized as a risk factor during pregnancy. Community members identify the importance of taking care of health during pregnancy, but they struggle to access quality medical services. As a result, they rely on guidance from friends, family members, and even social media which may be contrary to medical recommendations.

Community members recognize that older mothers are a high-risk category because the older the age of the mother, the more appointments and medical exams are necessary. They recognize this as a source of stress due to high costs. There is confusion on the prescriptions given by medical providers to address chronic disease in pregnancy.

Community members also believe that the younger the mother, the stronger she is to carry a successful pregnancy. At the same time, there is a clear stigma surrounding teen pregnancy, and given expectations of “machismo” within Hispanic culture, teen mothers can often find themselves alone during their pregnancy journey. In contrast, providers view the perception of “healthy young mothers” as an oversimplification that does not consider additional factors contributing to a successful pregnancy, such as nutrition and healthy weight. Providers recognize that young mothers may develop health risks due to their stage of life and conflicting priorities.

*“I also believe that if we take advantage of what is available nowadays, which in this case are medical services, vitamins, and others, then maybe we can give a better quality of life to our children.”*

– Spanish-speaking community member; translated

*“I’d say that it depends on the age range in which it [the pregnancy] is calculated. Because it is riskier. Well, if you are very young, it has its risks, and if you are very old, it also has its risks.... Because imagine if you were 60 years old—and there have been cases—and it works out perfectly. But yes, it has its risks.”*

– Spanish-speaking community member; translated

*“It [obesity] does play a role. For example, if you are a little overweight or chubby and you get pregnant.... I’d say that, also, you can be at risk, and it can be detrimental to the pregnancy.”*

– Spanish-speaking community member; translated

*“While a young pregnant mom, even in her teen years, can be stronger, many times they require more attention from providers. Either they want to stay skinny, and they don’t recognize the importance of healthy nutrition during pregnancy, putting the baby at risk, or they don’t care about healthy choices and keep eating empty calories that as well put at risk the proper development of the baby.”*

– English-speaking healthcare (medical) provider

## EMOTIONAL STATUS OF PARENTS MATTERS

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The stress that many women and men endure affects their health. For community members, stress can also mean “taking it out on the baby.” Finances are one of the greatest causes of stress, along with immigration and social support status. It can feel impossible to take care of children properly when they must also manage their households and spend long hours at their jobs—which do not offer flexible time for sickness, doctor appointments, or childcare—with little support from partners, extended family, or the community at large.

Providers also recognize the stressful circumstances of their clients and the impact of that stress on their health. Pregnant women face increased stress when they do not have an ID, or are worried about their husbands/partners driving without a driver's license, or are dealing with any other issues associated with being undocumented. Even after childbirth, it may lead to sustained bonding failure. Pregnant adolescents particularly face increased stress levels. Teen mothers are stigmatized because of their age and the view that they are destined to be a failure in their future parenting—a view that sometimes even comes from their own parents—on top of being victims of discrimination for their accent or country of origin.

*“Everything that the mom goes through when she is pregnant, the child feels it.”*

*– Spanish-speaking community member; translated*

*“I don't have anyone here either. I try to make a routine, so I don't get stressed, so I don't get depressed, and so on, but, even so, I mean, at the end of the day, you get home and there is no one there. No matter how busy you are all day long, you reach a point where [...] your husband works, you are with your child 24/7.”*

*– Spanish-speaking community member; translated*

*“We need support maybe, meetings, parties, whatever you can call it. I think that this way we can help people get to know each other. Because maybe they can help someone, and this person can help someone else. Okay, so I think that unity is strength, and here if we get together as a family we can get ahead. But to do that you have to make yourself known and get to know each other.”*

*– Spanish-speaking community member; translated*

*“I just learned this word, what was it, um, ‘post-partum depression.’ I didn't know that existed, now I am more prepared as a dad for my second child to support my wife.”*

*– Spanish-speaking community member; translated*

*“Teenagers are not ready to be moms...then a surprise pregnancy happens. As a result, and given the machismo in our community, the father leaves them alone at the most difficult time of their lives. Financial need pushes the teen mom to start working, and she doesn't have time to take care of her pregnancy. The baby is born, and mom goes right back to work, leaving the baby with a babysitter who has another 4 to 5 children in unhealthy conditions. Mom is not fully recovered from the delivery, and baby gets sick. All this emotional stress and the lack of social support starts very early in their pregnancy. This is very common in the area.”*

*– Spanish-speaking healthcare (social services) provider; translated*

*“Under stressful external circumstances pregnant women may face on daily basis—either the husband was arrested for not having a driver license, or they don't have a job, or the uncertainty of what is going to happen under the new government, when my family is going to be deported.... Then, the stress hormones released in response to these traumatic concerns—and the chronic stress in general—can be a contributor of*

*pre-term births or interfere with the natural bonding process. Infants and moms can exhibit signs of distress which cause difficulty breast-feeding, excessive crying, or difficulty sleeping. All those can increase the risk of infant mortality.”*

*– English-speaking healthcare (medical) provider*

*“The success of pregnancy in adolescents depends in big part on their social support received from their family circle and partners. They already have to deal with being judged negatively for a variety of reasons, including their youth, not being fit to be a mother. Then, to avoid judgment, guilt, and shame, they stop attending school, skip medical appointments. Then, their emotional health is affected as a result of the stigma, which will affect the well-being of mom and baby.”*

*– English-speaking healthcare (medical) provider*

### POSTPARTUM PERIOD IS EMPHASIZED

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The postpartum period is perceived to be a period where women and men can exert more control over their lives and families than the prenatal period, which is more dependent on external forces and the bureaucracy of the healthcare system. Women and men, as well as providers, focus on the role of nutrition and breastfeeding as critical to infant health. Providers recognize that moms are generally willing to follow this recommendation. However, they note that conditions in many places where women work do not allow them to pump milk, so their milk supply often decreases. They also focus on accident prevention.

Providers recognize the importance of establishing a bonding relationship between parents and providers during the prenatal period. They perceive that some parents feel or wish to be more on their own once the baby is born. In addition, providers also note that parents are dealing with bills for prenatal care and delivery, which also may prevent them from coming to regular postpartum appointments with their newborn babies.

Both community members and providers commented on the influence of *la cuarentena*. In Hispanic cultures, *la cuarentena* is a postpartum 40-day period when new moms rest, recover, and focus on bonding with their baby while they are cared for by relatives or friends. They abstain from certain activities, including intercourse, and focus on healing. Many people believe that *la cuarentena* can help reduce post-partum depression and infant mortality, as well as encourage healthy birth spacing and quality sleep. Some community members associated their lack of social support or the need to go back to work, either for financial reasons or for lack of benefits offered by their companies, with difficulty abiding *la cuarentena*.

*“They get sick less. In my case, I have always breastfed, and now I am breastfeeding my daughter and thank God she has not gotten sick like that. I say that breastfeeding helps a lot.”*

*– Spanish-speaking community member; translated*

*“It’s important to breastfeed, mainly because you can’t compare bottled milk to breast milk. Because breast milk has the nutrients—they help the baby develop and grow.”*

– Spanish-speaking community member; translated

*“Today, Hispanics or Hispanic mothers do not breastfeed their children because of lack of time.”*

– Spanish-speaking community member; translated

*“There are women who, unfortunately, want to breastfeed their children, but no, they can’t. They do not produce [breastmilk]. Or it is the choice of some women [to not breastfeed], mainly teenagers.”*

– Spanish-speaking community member; translated

*“For me, la cuarentena has been very valuable. Your mood changes, you just start crying out of the blue, but you have someone next to you that understands you without judging you. I think that a lot of accidents with babies are associated with the isolation that many mothers live in. We need a break, and here everything is work, and even if you have a partner or husband, he is working or tired.”*

– Spanish-speaking community member; translated

*“La cuarentena in Guatemala and in many other Hispanic countries is very common, strictly observed, and expected by doctors. Having your mother take care of you and your baby for 40 days can support simple things like delicious, nutritious food or giving you a chance to take a good nap while they are taking care of the baby. [It’s] 40 days to heal and to bond with your newborn.”*

– Spanish-speaking healthcare (social services) provider; translated

*“They talked a lot about how here they can’t do the same kind of things that they would have done if they were having babies at home. They don’t have extended family to take care of them or bring them their special foods. [...] We talked about, like, breastfeeding and supplementing with formula some, but a lot of them—they’re younger. I think a lot of them feel like, well, I’m here in the United States, I’m going to raise my baby the way they do it here. I’m not going to stay in for 40 days.”*

– English-speaking healthcare (medical) provider

*“So that’s [la cuarentena] a tradition where the women stay, and they are cared for, and their only job is resting and nursing. But here, we are asking people to bring their newborns to the pediatrician at two weeks. [...] And so for some of them, that’s their tension, like, I’m supposed to stay home and rest, but they’re telling me I need to leave.”*

– English-speaking healthcare (medical) provider

## CONFUSION ABOUT SAFE SLEEP

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There is confusion about whether babies should sleep on their back or on their stomach. Some of the confusion stems from a perceived lack of clarity on the dual medical recommendations of sleeping on the back and engaging in tummy time while awake. Some parents are aware of safe sleep guidelines but still practice unsafe sleep habits even when advised not to because they perceive they have no other choice. It is not unusual to find families of four or more renting a small bedroom where there is no space for a crib. Sometimes, generational and cultural traditions are the default mode for behaviors and can be hard to break, but men and women also do trust medical advice when offered consistently and frequently. There is also confusion about the difference between blankets and swaddles, as well as pacifiers, and how to appropriately regulate temperature for infants.

Providers are aware of the confusion about safe sleep among their clients and view it as a primary cause of infant mortality. They focus much of their patient education on safe sleep practices. They strongly associate unsafe sleep practices with generational or cultural reasons. Some providers highlight the need to better identify the source of the confusion. Some providers recognize the issue of space, while others overlook the impact of living conditions.

*“If they sleep in the crib, they’re going to feel hot or cold.”*

*– Spanish-speaking community member; translated*

*“I feel more relieved [now] because as the doctors say, she goes in her crib, and I feel good that she does not have the risk of sleeping with us and that we crush her.”*

*– Spanish-speaking community member; translated*

*“You have to make them tamales [meaning: ‘wrapped’ in English], so they don’t get scared, and when they are asleep they don’t jump. But not here, here you have to put them to sleep almost naked.”*

*– Spanish-speaking community member; translated*

*“I understand the importance of safe sleep and even know how to get a crib free of cost. I wish I would have space for the crib. I had to stop working and we can’t afford more than the bedroom we live in right now with my other three children and my partner.”*

*– Spanish-speaking community member; translated*

*“The size [of the pacifier], the shape, the hardness, you have to take it into account.”*

*– Spanish-speaking community member; translated*

*“As a provider, we need to be more intentional, include motivational interviewing to understand the dynamics that those families, our patients, live in. An empathetic question, such as, ‘What prevents you from keeping your baby sleeping in a crib alone? Money, space, cultural tradition, myths, education?’ can help to understand their personal circumstance and maybe the recommendation could be a baby box.”*

*– Spanish-speaking healthcare (medical) provider; translated*

*“With the Hispanic and Latina moms, like, they're often wanting to sleep with the baby. I saw that in the hospital a lot, and I just remember, like, sort of giving that education and feeling a little bit like, oh, this doesn't really feel like culturally competent or something. And like, how do you—how do you make safe sleep when it doesn't, like, maybe match, like, other like familiar or cultural traditions.”*

– English-speaking healthcare (medical) provider

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## THEMES IN BARRIERS TO ACCESSING SERVICES

We identified the following eight subthemes. Quotes are sourced from transcripts from the community focus groups and small group interviews among providers.

### LACK OF PROVIDERS

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Some providers do not agree that there is a shortage of personnel, but others argue that there are shortages in primary care providers taking new patients, or availability of OBs, nurses, midwives, and pregnancy groups and classes that are accompanied by a medical provider. An important concern is that OBs are booked for many weeks, leading some women unable to receive care until their 2nd trimester. Some providers highlighted that some prenatal care centers are not operating at all due to lack of providers, which brings a wave of transfer patients to their facilities and increases their workload.

Women and men also express concern that OBs are booked for many weeks. Many women receive prenatal care in their 1st and part of their 2nd trimesters from community-based clinics that do not provide delivery services. When women are released from these early prenatal care providers at the end of their 2nd or beginning of their 3rd trimester, they are left to look for a provider who will attend the delivery. Some OBs, however, will not take new patients who have advanced pregnancies. Some parents express stress caused by the rotation of providers and clinic locations, especially in the final weeks before their delivery. Other women express their concern about access to care during ER visits for pregnancy issues, especially close to their delivery. The services they received were limited; even with pain and discomfort, they reported not receiving an ultrasound and were sent back home.

Men and women do perceive a good number of social service providers, and they are grateful for the assistance they can receive throughout Elkhart County.

*“Referring a patient to [...] providers in week 32 is a toll for a patient. It is starting over at a crucial point in the pregnancy. Yes, they have great providers, but the patient is not going to have the same confidence in making phone calls to ask questions in Spanish, the billing process is going to be different and very limited on discounts, maybe transportation will become a bigger issue with the distance, among other things. All this adds up and increases stressful circumstances that are going to affect the health of the expectant mother.”*

– English-speaking healthcare (medical) provider

*“I was 15 when I was pregnant, and at the hospital [...], they refused to do an ultrasound—they said that I looked good, I was too young to have a complication. The pain persisted—a week later I could not handle the pain anymore. I went to a hospital in [another city], and they did an ultrasound and induced the delivery immediately. They saved the life of my baby. The umbilical cord was around his neck”*

– Spanish-speaking community member; translated

*“My experience giving birth was scary. I arrived at the hospital with 3 centimeters of dilation and in 3 hours I moved to 10 centimeters. The doctor never showed up. The nurses didn’t do that much and said that there were no doctors at the hospital. My baby did it alone making his way to this world. The doctor arrived 15 minutes after I gave birth, and to my surprise, he said everything happened as expected. I even had to tell him, ‘Doctor, I haven’t delivered my placenta.’ Very scary. Thank God this was my third baby, and my husband was with me the whole time, and my aunt was there to translate for me.”*

– Spanish-speaking community member; translated

## LANGUAGE AND CULTURAL BARRIERS IN HEALTHCARE

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The lack of availability and accessibility of Spanish-speaking providers creates barriers to accessing healthcare. This generates problems with miscommunication and lack of trust. It increases the lack of confidence in patients to address their medical concerns, and they do not even feel comfortable asking for clarification or general questions about their health condition.

There is a lack of communication and congruency between health records of the home country and the U.S. based record system. Spanish-speaking individuals may not return to a healthcare practice where they cannot receive care in their language or medical practices are not culturally congruent with those they are accustomed to. There is a low use of resources when referrals are offered or when they cannot receive service due to a language barrier or because the referral information itself is in English. In addition, there is a concern among both patients and providers about the accuracy of translation and interpretation.

Providers do not always have time to listen to patients discuss their cultural beliefs about care during pregnancy, which creates cultural barriers. According to providers, these cultural beliefs may include myths that can prevent supporting the well-being of the mother and infant. Sometimes, especially in a rushed environment with a demanding patient schedule, providers are quick to request an interpreter as soon as they hear a strong accent, without asking the patient’s permission or preference.

*“I arrived here when I was seven months pregnant, and, well, the most complicated thing for me was the language. I don’t speak much English, so, um, [I] was mostly*

*[concerned about] that at the time of delivery because you are worried about how your child is doing. You want to know how he was born, what he has, and so on.”*

– Spanish-speaking community member; translated

*“Yes, I don’t speak English, but when I went to my first appointment for my first baby, they gave me the paperwork in Spanish, and I couldn’t understand it. Not because I didn’t speak Spanish, but because the translation of the document was poor—I was not able to move on from the first page. The front desk person was frustrated because I expressed my concern.”*

– Spanish-speaking community member; translated

*“Yeah, bringing on more staff that is bilingual. That’s the first and foremost [issue], bulk up our staff that is bilingual so that we can serve more—more clients. So, whether that’s men’s mentors and coaches, women’s mentors and coaches, as well as nursing staff, including bilingual NPs.”*

– English-speaking healthcare (medical) provider

*“There are assumptions made, and there’s also [...] the language barrier. If I need to [...] check in and make sure that I do [...] a good assessment, I’m going to have to get my interpreter. I’m gonna have to get [the interpreter], pull up the video screen, [...] I’m just gonna assume [the interpretation is] fine.”*

– English-speaking healthcare (medical) provider

*“Hispanic patients don’t feel comfortable asking questions. I recalled many of the patients nodding when the doctor talking used big words such as preeclampsia. When the consultation ended, I asked them if they understood what the doctor said and the recommendations, and they said no. That was scary for me, because I knew that we were not going to see them in another two to three months, but for lack of language and courage, they could put at risk the life of mom and baby.”*

– Spanish-speaking healthcare (medical interpreter) provider; translated

*“I know that I have an accent, and even with an accent, I finished my MBA in Indiana. I feel disrespected when—whether in person or by phone—a provider or staff person listens to my accent and immediately requests an interpreter, even without my consent. It is a complete lack of cultural sensitivity. I know there is a protocol to bridge the gap when a language barrier exists, but it doesn’t always apply. This situation is more noticeable when the provider or staff person assumes that when the patient has an accent, that equals the patient doesn’t have documents.”*

– English-speaking healthcare (social services) provider

## DIFFICULTIES UNDERSTANDING HOW THE U.S. HEALTHCARE SYSTEM FUNCTIONS

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The differences between the U.S. healthcare system and the healthcare system in an immigrant’s country of origin can feel vast, overwhelming, and hard to understand. The

differences include how to schedule appointments, how to access pharmaceuticals and contraceptives, delays associated with care, and the process of receiving results, referrals, and billing. It can leave patients feeling frustrated, discarded, and like they are not being taken seriously.

They are used to having long consultations with a doctor; they expect to be told results of labs and receive a hard copy of those results; they do not know where to get access to medications or contraceptives that were readily found over-the-counter in their countries of origin, and further, they do not expect the requirement to show an ID to be able to pick up some medications; and they do not understand the inconsistencies with how OBs transfer or refer women during pregnancy. In their countries of origin, there are few restrictions on the number of doctor appointments or ultrasounds; it depends on the needs of the baby and mom. In many Latin American countries, there are stricter laws in place to protect the health and well-being of every baby and mom. In the U.S., patients often fear the bill they will receive, and that reduces the patient's trust in the healthcare system. When limited by the number of ultrasounds allowed in traditional care, in some cases that increases the urgency to visit other providers, so that they can see the baby or hear the heartbeat to increase bonding, reduce stress, and feel assured their baby is doing well.

*“For me, it was very difficult because I had to adapt to a system I wasn’t used to, [that was] different from the one I was used to.”*

*– Spanish-speaking community member; translated*

*“We could never get the medical attention we needed at the moment of the emergency.”*

*– Spanish-speaking community member; translated*

*“They don’t talk much about how you can apply for Medicaid, that you can get prenatal care here—in many places you can get it. But later on, for the [other children], it became a little easier because I knew places that cared and would help me, where it wouldn’t be so expensive, where Medicaid helps you a little and you pay for the other little bit. But when I had just arrived it was very difficult for me, I struggled a lot, it was very expensive, I didn’t work.”*

*– Spanish-speaking community member; translated*

*“In my first appointment, they asked me if I already had an ultrasound, and I said, yes, it was done in Honduras, and I didn’t have the results with me. But it counted as one out of the two they recommended. So, I didn’t feel comfortable, I wanted to see my baby. Then, I started going to another place.”*

*– Spanish-speaking community member; translated*

*“I couldn’t get on my husband’s health insurance because it was not the enrollment period. After applying three times to Medicaid, I got into it in October, and my baby was born in December. Yes, of course it affected the quality of prenatal care I received, plus the stress I was living in.”*

*– Spanish-speaking community member; translated*

*“[They’re] new to the country. Maybe [they] have already 3-4 children, you know, but don’t understand medical care in this country, or the priorities that we think are important are not important in their culture.”*

*– English-speaking healthcare (medical) provider*

*“People are used to being able to locate and visit their doctor at night, on weekends, or holidays. Having to go through the “Ask-a-Nurse” system via phone call [in English] to locate an on-call doctor, often results in unnecessary visits to the emergency room and very costly bills.”*

*– English-speaking healthcare (medical) provider*

*“Finding ways to educate newcomers about how things like the healthcare and education systems work in this country is necessary.”*

*– English-speaking healthcare (medical) provider*

## LOW HEALTH LITERACY

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Patients may not understand or follow their providers’ instructions. They do not get the complete picture of their health condition and often do not understand why they are being prescribed certain medications. There is a particular lack of understanding regarding high-risk pregnancies, gestational diabetes, and preeclampsia. Perinatal health conditions are left unattended, and treatments are delayed, or they do not know what to do to address the problem. Due to intimidation and cultural gaps, even in the presence of an interpreter, they do not ask questions. Many know what preterm birth is but do not have a complete understanding of the issues that may cause preterm birth. There is a lack of knowledge about the importance of pre-conception health and how pre-existing, uncontrolled health conditions can affect pregnancy and birth outcomes.

Providers may fail to ensure understanding of medical conditions and the reasoning behind their instructions. Patients may be left with gaps in understanding that put them at higher risk for dangerous conditions that could otherwise be prevented or detected before an adverse effect.

*“They told me, ‘it’s to avoid pre-eclampsia,’ and that’s it. They didn’t tell me anything, and I tried to talk, but they didn’t tell me anything. They just said, ‘just do it,’ and ‘wait for the test results.’”*

*– Spanish-speaking community member; translated*

*“Well, sometimes not all the indications given by the doctor are good. Because sometimes, well, I also had gestational diabetes, and my pregnancy was very high risk. And for example, when you are pregnant, you are carrying a baby in your belly, and you get very hungry. And they tell you to eat a small portion and you don’t get full.”*

*– Spanish-speaking community member; translated*

*“I went to the doctor, and they started with these difficult terms I don’t understand. They gave me a brochure when I was leaving, but it was not enough. I missed the group educational sessions they used to run. I attended it during my first pregnancy. Now it seems that they can bill more for individual appointments, but patients are not more happy.”*

– Spanish-speaking community member; translated

*“There is a lot of material that has been translated to Spanish. However, it still fails to communicate effectively. A lot of our patients have a very basic literacy level. In some cases, they do not know how to read or write. So, when they are given big packets of information, they do not know what to do with them.”*

– English-speaking healthcare (medical) provider

*“I am pregnant, and I just learned in a recent educational presentation what infant mortality is. I don’t want my baby to become part of those statistics. For me, that presentation was fundamental. I wish I would have learned this concept earlier in my pregnancy—even more when I have a high risk pregnancy.”*

– Spanish-speaking community member; translated

*“There is a lack of cultural sensitivity in the healthcare system. Asking questions like, ‘How comfortable do you feel reading?’, ‘Do you prefer material that has more images?’, or ‘Would you like a video explanation?’ [are important]. Simply having more options available for information delivery at the sites will make a huge difference in the relationship with our patients and better outputs.”*

– English-speaking healthcare (medical) provider

*“Providers are busy, and patients get frustrated waiting to see the doctor for 1 to 2 hours, and then the consultation is 5 minutes long. The faces of patients change completely when, even in those 5 minutes, the doctor asks if they have any questions or makes a specific reference to the needs or barriers they mentioned in the previous appointment. Patients lack quality attention. There is a need to be treated as a unique individual, with individual needs and limitations. When that trust is built, mutual understanding starts to bloom because the window for asking questions finally opens. There is no understanding without questions asked.”*

– Spanish-speaking healthcare (medical interpreter) provider; translated

## FEAR ASSOCIATED WITH IMMIGRATION STATUS

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The lack of legal documentation (i.e. social security number, work authorization, permanent residency, driver’s license, etc.) influences immigrants’ access to healthcare, and, by default, deprives unborn American citizens of fundamental rights, such as the opportunity to receive Medicaid coverage. Undocumented immigrants often work long shifts and rarely ask for time off for fear of losing their job or pay, leading to missed/skipped appointments for prenatal and postpartum care. Efforts at the federal level in 2025 to remove birthright citizenship and deport

immigrants through executive order, although challenged by courts, have exacerbated fears and stress.

*“People don’t feel comfortable going to the hospital right now. For example, I qualified for Emergency Medicaid, but I am afraid and decided not to apply. I don’t want my data to be in the government’s system. However, I know of people who started delivering their babies at home because of their fear about their immigration status.”*

*– Spanish-speaking community member; translated*

*“Sometimes you get more information from your friends because the provider you are visiting does not refer you to other places. It is a sad competition among them. However, there are places that run weekly parent/pregnant women meetings, and they give you diapers, and other goodies needed for your baby. I even got a crib, but my neighbor was the one who told me about them, not my provider.”*

*– Spanish-speaking community member; translated*

*“Some companies provide up to four weeks unpaid maternity leave, some none. However, they [mothers] are in fear of losing their jobs and living day by day. Companies in the area care about production, production, production, and those jobs are quickly replaced. Then, they’ve barely even given birth when they are already back to work. Their immigration status makes their job the priority versus their care for their newborn. This is the daily dilemma of our immigrants.”*

*– Spanish-speaking healthcare (social services) provider; translated*

*“You go to places you trust, and many times trust is built when you find people that look like you, people with empathy...not just people who speak Spanish. When you find that trust, you become loyal, and positive outcomes, particularly for minority patients, occur.”*

*– Spanish-speaking healthcare (social services) provider; translated*

*“Many mothers are stressed about not having legal immigration status, and to be so focused on that matter—it’s causing them to deviate their attention away from their prenatal care. This makes the bonding process between the baby and the mother difficult to achieve, putting their pregnancy and the health of their newborns at risk.”*

*– Spanish-speaking healthcare (medical) provider; translated*

*“The threat to remove birthright citizenship will likely increase the undocumented mother’s fear of being deported and reduce the likelihood of seeking medical assistance during delivery. Maybe mothers are going to start delivering babies at home. This would also likely increase the risks for both the mother and the baby.”*

*– Spanish-speaking healthcare (medical) provider; translated*

## FEAR OF JUDGEMENT

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Fear of discrimination and unfriendly treatment influences some women who avoid seeking care. The trauma that some immigrants have suffered in their journey to the U.S. causes them to avoid triggers, including those in the healthcare setting. Teenagers are sometimes fearful of reaching out, thus delaying the start of prenatal care. Some women have not been seen by a practitioner in years, leading to uncontrolled medical conditions throughout pregnancy. In general, after the federal executive orders in 2025 regarding immigration issues, fear is more noticeable among all Hispanics, including those immigrants with legal documentation. Fear is particularly acute for new immigrants who may not have a support system established that can offer guidance.

*“It would be good if they were a little more attentive to give you what you need. I would like that, to be a little more cautious.”*

– Spanish-speaking community member; translated

*“In the current place I work, we do not offer prenatal care. So, we are obligated to refer pregnant women to other places. When we tell them, ‘No, we cannot take care of your pregnancy here,’ their faces reflect a total shock—one can even perceive their fear and intimidation resulting from having to go to another facility where they do not know how they are going to be treated.”*

– English-speaking healthcare (medical) provider

*“After the executive orders related to immigration were signed, I have noticed unfair treatment, even at the business level. Many of my Hispanic peers, who are American citizens, have expressed the same to me. There is a noticeable increase in bias and unfair behavior because of our looks or accent. I feel like we are going back a hundred years! If we, as Hispanics with U.S. nationality, feel like we now need to carry a U.S. ID to demonstrate our rights, then it is not hard to understand the difficulties that undocumented Hispanic immigrants in our community are facing. But, not providing access to care for pregnant women directly affects the right of unborn American citizens to thrive....”*

– English-speaking healthcare (social services) provider

## HIGH COSTS

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Low wages and lack of health insurance benefits can make the cost of services such as lab work and prenatal care an impediment to accessing and continuing healthcare or seeking specialist care, especially when patients are balancing other expenses.

Indiana currently has limited Medicaid coverage for undocumented immigrants while other states provide full coverage; Emergency Medicaid (Package E) covers only the delivery and excludes prenatal care; Package B covers prenatal care but does not cover contraception after birth. These kinds of gaps make it hard to understand billing for lab work and/or emergencies,

and they lead to confusion about which providers accept what types of coverage. Even when they have coverage, women are overwhelmed by the elevated cost of specialist appointments and the frequency of those appointments.

*“They sent me to a specialist in South Bend and it is very expensive there. And in fact, I’m stuck with that bill because I’m not working yet.”*

– Spanish-speaking community member; translated

*“I stopped coming to my appointments because the bills don’t stop. Facility bill, lab work bill, radiology bill—I was swimming in bills. I just put my pregnancy in the hands of God. One day, I was not feeling good, and I tried to set an appointment, but they told me I have to make a payment first in order to see the doctor.”*

– Spanish-speaking community member; translated

*“I’ve never understood why pregnant women are on this [Emergency Medicaid] package. Those babies are going to be citizens. The best way to ensure a good outcome for baby is to give Mom good prenatal care.”*

– English-speaking healthcare (medical) provider

*“Yeah, if they could at least expand [Medicaid] so that everybody had coverage in Indiana for prenatal care, that would make a huge difference.”*

– English-speaking healthcare (medical) provider

*“Part of what can happen is that, you know, moms will skip visits, or they will skip labs because, I mean, those initial labs are \$1,500 bucks. You know they can be, yeah, I mean, they can be very expensive. Ultrasounds. Kind of a minimum of \$250, I would say. And that’s just the facility charge, and you have a radiology charge, and you have, you know...”*

– English-speaking healthcare (medical) provider

*“Being charged for missed appointments makes it more likely for some patients to decide to stop coming to their appointments. They stop coming because they already have a debt from their missed appointment, and that adds up to what they would have to pay for any other appointments. This makes medical services difficult to afford for many patients.”*

– English-speaking healthcare (medical) provider

*“We are getting patients that just arrived in the U.S. They do not have a job yet, and sometimes they are in the dilemma of whether it is better to go to the doctor or buy groceries for the week. So, adding a fee for missing appointments prevents them from coming back to the facility.”*

– English-speaking healthcare (medical) provider

## LACK OF SUPPORT SYSTEMS FOR CHILDCARE AND TRANSPORTATION

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Not having a reliable support system that can assist with childcare and transportation makes it difficult for patients to attend medical appointments regularly.

Home visits have also been limited or completely suspended due to lack of funding. Many women lack a driver's license, drive unsafely due to lack of training and practice, or cannot get a ride because they are new to the area or have an appointment when no one is available to help. Healthcare center policies penalizing lack of attendance or punctuality often feel like punishments with little or no explanation, especially when patients usually do not understand or are not made aware of such policies. The traditional *cuarentena* is not observed due to work demands.

*"I arrived late to one of my prenatal appointments because my ride could not leave on time from her job. I still knew it was important to attend, and I arrived 15 minutes late. They wouldn't let me try to explain, just told me that I had to pay \$50 as a penalty for no show, and that I needed to reschedule—without knowing that I wouldn't have \$100 again to pay for my ride. I skipped the next appointment—I couldn't afford it."*

– Spanish-speaking community member; translated

*"We hear a lot of 'I could not make it to my appointment because I did not have anyone to drive me here,' 'My husband gets off of work late, and I could not come,' and 'My kids go to school, I must wait 'til they get home.' The lack of transportation has always been a barrier."*

– English-speaking healthcare (medical) provider

*"When hosting parenting classes, we noticed that the ones who could not attend regularly would say, 'I couldn't find a ride here,' or 'I don't have anybody to take care of my children during the class.' When we decided to offer childcare during class time, the attendance rates increased."*

– English-speaking healthcare (medical) provider

*"There's more barriers and obstacles like, you know, like, she says, if you don't have, you know, someone to translate, but you don't have a car, you may not have the money, you may not have the tools, you may not have the education where it's like, you know, maybe back in your culture it's just to, like, do home remedies and you know, do other things."*

– English-speaking healthcare (medical) provider

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## THEMES IN NEEDS & GAPS

We identified the following three subthemes. Quotes are sourced from transcripts from the community focus groups and small group interviews among providers.

## LACK OF CULTURALLY COMPETENT, SPANISH-LANGUAGE HEALTH EDUCATION

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There is a massive need for educational programs on the topics of reproductive health, pre-conception health, prenatal care, labor and delivery, birth spacing, infancy, early childhood education, preventive medicine, and mental health, designed for the Spanish-speaking community.

Some women, regardless of age or nationality, may have only finished primary school. Young women, in particular, lack appropriate sex education and education about reproductive health. They appreciate help from WIC, Women's Care Center, and Healthy Babies. Participants expressed a need for a list of resources and providers they could tap into during their pregnancy and postpartum period.

*"I have also attended classes here for moms. [...] before I had the baby and now after the baby is born, they offer classes, as well as classes for moms. This is great for us!"*  
– Spanish-speaking community member; translated

*"I am alone in this country, just me and my husband. My pregnancy is high risk. We are the only Hispanics in our neighborhood, and we don't speak English. For me, the educational presentations given in Spanish by organizations like yours are fundamental for my mental health. I have people to talk to."*  
– Spanish-speaking community member; translated

*"Knowledge is power, so making sure they're well equipped before delivery and then any educational needs they have following that."*  
– English-speaking healthcare (medical) provider

*"When it comes to the education of future nurses, doctors, medical assistants, and other healthcare workers, it should be ensured that cultural competency is part of the curriculum. That has been missing."*  
– English-speaking healthcare (medical) provider

*"When talking about nutrition, there is a need for material adapted to the Hispanic community, especially regarding nutrition. So, we have to create our own material that could be more effective for the health education of our Hispanic population."*  
– English-speaking healthcare (medical) provider

## INADEQUATE HOUSING/SLEEPING SITUATIONS

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The limited housing situation of many low-income Hispanic immigrants means many sleep in crowded rooms that are dangerous to newborns, elevating the risks of SUIDs due to unsafe sleep practices. Sometimes, adherence to certain cultural norms or myths can exacerbate the risk associated with sleeping situations.

Families may receive a crib or other form of safe sleep device, but they do not have room to set it up. Co-sleeping is a cultural practice that is not recognized as dangerous by the Hispanic community. There is concern that many Hispanics overwrap and overheat babies.

*“My mother and grandmother told me to stay close to my baby—[they said] even sleeping with her was the safest way. Also, they recommended putting blankets on her at night. It is cold and she can get sick. Here, all those myths were corrected, and my child is healthy and safe.”*

– Spanish-speaking community member; translated

*“So, families living, renting a room within an apartment or within a house from somebody else.... Families living in a room don’t have space to put up a crib for their baby or the free pack ‘n play that we can give them even if they wanted to.”*

– English-speaking healthcare (medical) provider

*“I mean, to have a good separate safe space for a baby. I mean, we can give them education, we can even give them a pack ‘n play, but some don’t even have, you know, their housing is not stable enough to even— or have enough room to even set up a pack ‘n play.”*

– English-speaking healthcare (medical) provider

*“There’s a lot of co-sleeping, and if that’s what you know to be true, to sleep with your baby and to keep your baby super bundled. Well, if they don’t think there’s anything wrong with it, you can’t really, you know, try to force change if they don’t, if they think it is the best thing for their babies.”*

– English-speaking healthcare (medical) provider

*“Families sharing housing because housing is so expensive that you have a lot of families doubling up.... Then sleeping conditions for babies are not as desired.”*

– English-speaking healthcare (medical) provider

*“Unfortunately, in our home visits we still find families living in one bedroom, sleeping on waterbeds with babies. They may see the risk, but they are surviving! Unfortunately, those are some of the causes associated with infant mortality in Elkhart.”*

– Spanish-speaking healthcare (medical) provider; translated

## FINANCIAL INSECURITY

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Wage labor and long hours at unstable employment contribute to unhealthy behaviors, such as missing appointments, poor nutrition, lack of exercise, anxiety, and stress. Community members feel they are forced to choose between a job and healthcare. Many Hispanic immigrants work in factories and other similar jobs that are typically low-wage, where they receive few to no benefits or sick leave, and they fear losing their jobs to visit the doctor. Maternity leave, if it is offered, is often unpaid and does not accommodate the length of the traditional post-partum

cuarentena. Some workers may also not be eligible for maternity leave, when it is offered, and workplaces may not always offer accommodations to pregnant women. If a woman takes leave to deliver her baby, she may not be guaranteed the same position or retain her job after delivering. Many women return to work within a couple weeks of delivering.

*“My husband covered the expenses, and these expenses—it was very difficult. Sometimes I didn’t want to go anymore. I said—in fact, one time I did miss [an appointment], and the doctor told me, ‘It is very important that you come to your weekly appointment,’ and I, well, it was too much for me.”*

– Spanish-speaking community member; translated

*“You are absorbed by the work, you have to spend long days at work. [...] there are clinics that close at certain hours so it doesn’t work out. Sometimes you don’t have the permission at work to leave work and take the wives to the clinic, so that is a big time barrier.”*

– Spanish-speaking community member; translated

*“Here [...] they do not limit the jobs, that is, if we are pregnant [...] and I think that is very good, right? Because sometimes in our countries of origin they have us, like, you are pregnant, they limit you. Not here, and I feel that that is good, but, then the limitation... At least, I worked in factories... if you have appointments, then they give you the points that... you can... risk losing your job, right? So, I feel that [...] there is no balance as such. So, they accept you pregnant, but they don’t... they don’t understand that there are certain days, right, that you have to leave for a medical appointment. So, you think, my job? Or I keep the appointment I make? I’ll try to move it later... I don’t know.”*

– Spanish-speaking community member; translated

*“There’s just so much, like, financial hardship, jobs and then lack of support... So, I’m thinking of, like, you know, it’s such a strain to get your kid out the door from these, like, well visits, because who’s going to watch your other kid? Or, like, you only have one vehicle and your husband’s working. You can only come to the appointment between the hours of like 3:30 and 4:30...”*

– English-speaking healthcare (medical) provider

*“It is unfortunate to see more and more women who barely even deliver the baby and they’re already back to work. In this area, factories are just thinking about production, and on top of that, they don’t offer paid maternity leave. With the stress of losing their job, much less their specific position, they make the decision to go right back to work, putting their health at risk and their newborn’s—who is in hands of a babysitter with another three to four children”*

– Spanish-speaking healthcare (social services) provider; translated

## QUANTITATIVE

The themes relevant to the issue of infant mortality were identified through the lens of quantitative analysis. We provide descriptive statistics relevant to the three areas of inquiry and assessed across eight subthemes for 511 community members completing the infant mortality survey, which was carried out in conjunction with the demographic survey.

Specifically, in the quantitative analysis, we report the community characteristics and community prioritization of major modifiable factors such as health behaviors, social and economic drivers and clinical care factors, which contribute to poor birth outcomes and infant mortality. In addition, satisfaction ratings for prenatal health service provision in Elkhart County, and preferred communication channels for dissemination of a prevention campaign are included.

Table 4 maps NIHHC's Demographic Survey and Infant Mortality Survey measures to the three core study themes of Awareness, Knowledge, and Attitudes Towards Perinatal Health; Barriers to Accessing Services; and Needs and Gaps, in addition to the community characteristics. Appendices D and E provide examples of the surveys that participants completed.

**Table 4.** Summary of Demographic Survey and Infant Mortality Survey items and measures mapped to the study themes

<b>Study Themes</b>	<b>Subtheme(s) Reported</b>	<b>Core Measures</b>
<b>Community Characteristics</b>	<b>Minority population/vulnerable/ underserved: age and gender; place; and language proficiency</b>	<b>Ethnicity; language preference; zip code; gender</b>
<b>Awareness, Knowledge, and Attitudes Towards Perinatal Health</b>	<b>Health literacy</b>	<b>The meaning of the term infant mortality [Q1] [Q5] [Q6]</b>
	<b>Knowledge and perception of research-identified causes of infant mortality in Elkhart County</b>	<b>Causes of infant mortality [Q2]</b>
	<b>Knowledge of available health services</b>	<b>Knowledge of Emergency Medicaid and the WIC office [Q10] [Q11]</b>
<b>Barriers to Accessing Services</b>	<b>Social drivers of health impacting pregnancy and baby</b>	<b>For a successful pregnancy and healthy baby my life would be easier with ...[Q4] [Q7]</b>
	<b>Satisfaction with health services used in Elkhart County</b>	<b>Level of satisfaction with health care services you have received in Elkhart County area [Q12] [Q14] [Q15]</b>
<b>Needs and Gaps</b>	<b>Health behaviors impacting healthy pregnancy and baby</b>	<b>For a healthy baby and pregnancy, we need ...[Q3] [Q4]</b>
	<b>Information and services needed</b>	<b>We need more places that offer info on ... [Q8]</b>
	<b>Communication channels</b>	<b>Communication channels appealing to the Hispanic community to promote preventative health campaigns [Q9]</b>

Summary reports of key findings by study theme and subtheme follow. A full report of all descriptive statistical results from the infant mortality surveys can be found in Appendix G.

## THEMES IN COMMUNITY CHARACTERISTICS

Table 5 reports the results of the demographic survey, carried out in conjunction with the infant mortality cross-sectional survey. Results are tabulated according to three event type categories provided by NIHHC in Elkhart County targeting the Hispanic population of focus: (a) 2 Health Fairs, specifically one at a high school and one at a church; (b) 26 Flu Shot Clinics; and (c) 3 Outreach Events.

Of particular note are the high numbers of responses NIHHC was able to obtain at 31 community events. A total of 511 replies were collected. Respondents included 434 adults over the age of 18, with 17 youth under the age of 18 (3%). 91% (n=467) of survey respondents self-identified as Hispanic or of Spanish origin, with an average age of 32. 86% of NIHHC survey respondents (N=438) were from Elkhart County.

**Table 5.** Summary of demographic characteristics as reported in the demographic survey

Demographic Characteristics of Survey Respondents	Health Fairs 2 events	Flu Shot Clinics 26 events	Outreach 3 events	Total (n=511)
	Jun & Sep 2024 (n=162)	Oct & Dec 2024 (n=259)	Aug & Sep 2024 (n=90)	
<b>Age, n (%)</b>				
Under 18	17 (10)	0 (0)	0 (0)	17 (3)
18-24	1 (1)	35 (14)	10 (11)	46 (9)
25-34	44 (27)	66 (25)	35 (39)	145 (28)
35-44	42 (26)	44 (17)	25 (28)	111 (22)
45-54	18 (11)	61 (24)	6 (7)	85 (17)
55-64	5 (3)	20 (8)	4 (4)	29 (6)
65 and over	5 (3)	11 (4)	2 (2)	18 (3)
Prefer not to answer	30 (19)	22 (8)	8 (9)	60 (12)
<b>Gender identity, n (%)</b>				
Women	113 (70)	148 (57)	47 (52)	308 (60)
Men	36 (22)	109 (42)	43 (48)	188 (37)
Prefer not to answer	13 (8)	2 (1)	0 (0)	15 (3)
<b>Race or ethnicity (check all that apply), n (%)</b>				
Hispanic or of Spanish origin	159 (98)	221 (85)	87 (97)	467 (91)
Not Hispanic or of Spanish origin	3 (2)	38 (15)	3 (3)	44 (9)
<b>Language Proficiency, n (%)</b>				
Spanish	147 (91)	195 (75)	80 (89)	422 (82)
English	10 (6)	63 (24)	5 (6)	78 (16)
Both	5 (3)	1 (1)	5 (6)	11 (2)

Prefer not to answer	0 (0)	0 (0)	0 (0)	0 (0)
<b>Geographic Location, ZIP code, n (%)</b>				
46514	44 (27)	35 (14)	11 (12)	90 (18)
46516	19 (12)	49 (19)	19 (21)	87 (17)
46526	45 (28)	31 (12)	12 (13)	88 (17)
46528	41 (25)	10 (4)	6 (7)	57 (11)
46517	3 (2)	42 (16)	5 (6)	50 (10)
Other	4 (3)	92 (35)	8 (9)	104 (20)
Prefer not to answer	6 (4)	0 (0)	29 (32)	35 (7)
<b>Geographic Location, County, n (%)</b>				
Elkhart	155 (96)	228 (88)	55 (61)	438 (86)
Other	1 (1)	31 (12)	6 (7)	38 (8)
Prefer not to answer	6 (3)	0 (0)	29 (32)	35 (6)
<b>Geographic Location, Township, n (%)</b>				
Concord Township*	66 (41)	126 (49)	36 (40)	228 (45)
Elkhart Township**	86 (53)	67 (26)	18 (20)	171 (33)
Other	10 (6)	66 (25)	36 (40)	112 (22)

\*Concord Township. One of sixteen townships in Elkhart County, Indiana. Concord Township is covered by 5 Zip codes: 46514, 46515, 46516, and 46517.

\*\*Elkhart Township. One of sixteen townships in Elkhart County, Indiana. Elkhart Township is covered by 4 Zip codes: 46526, 46527, 46528, and 46553.

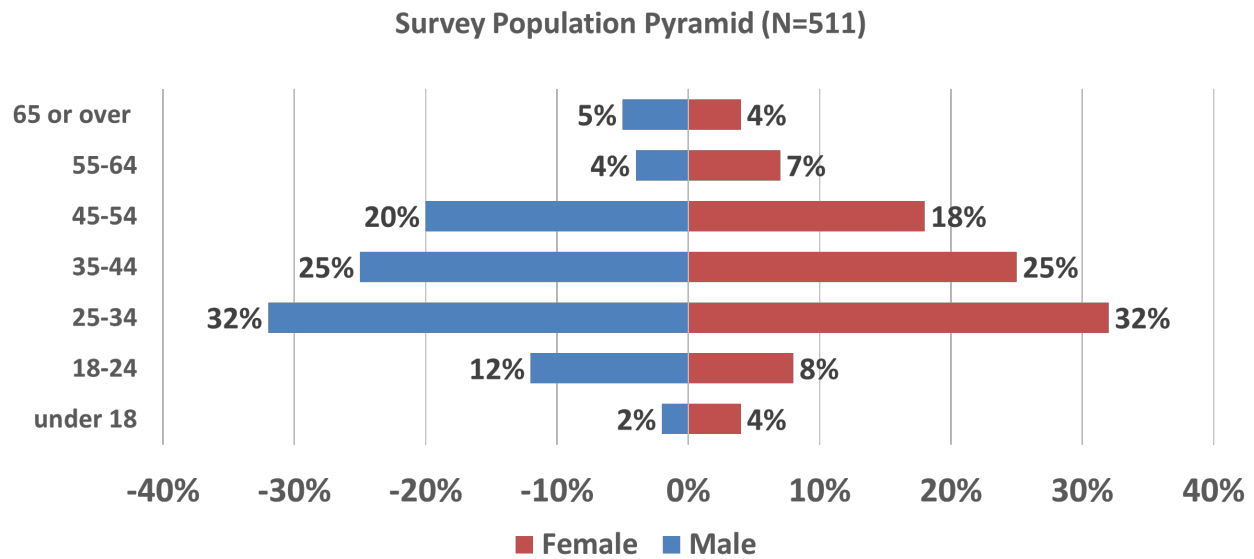
In what follows, we report the results from three subthemes: age and gender; place; and language proficiency.

Of note: We ran Pearson's chi-square and Fisher's exact tests on the principal variables highlighted by the demographic survey (race and ethnicity; place; gender; age; and language preference). The analysis determined no significant difference in age/gender with a mean age of 32 years; race/ethnicity and township ( $p < 0.052$ ); and race/ethnicity and language preference ( $p < 0.000$ ). The analysis also determined significance to men and women (gender) of the following factors for a successful pregnancy: Medicaid health insurance ( $p < 0.005$ ); a better understanding of the health system ( $p < 0.010$ ); and fluency in English ( $p < 0.016$ ).

## AGE AND GENDER

Figure 3 is a demographic population pyramid showing how the NIHHC survey population was distributed by age and gender. The pyramid shows a relatively broad base, indicating a small number of younger individuals (under 18), and a wider middle section, suggesting a growing population and a higher proportion of people in the working-age range. The top of the pyramid is narrower, indicating a smaller proportion of older individuals taking part in the survey.

Figure 3. Demographic survey population pyramid



PLACE

The majority of survey participants were living and working in two townships in Elkhart County – Concord (N=228) and Elkhart (N=171). The majority of men and women surveyed had a preference for speaking in Spanish 82% (N=422). 60% (N=308) of survey participants were female. The sample shows 70% (N=113) of the women attending Health Fairs completing surveys whereas male participants were more successfully surveyed during flu shot clinics and outreach activities.

Figure 4 shows the distribution of survey respondents by township. Data showed a good geographic spread across Elkhart and Concord Townships, with the highest rate of response in zip codes 46514, 46516, 46517, 46526, and 46528. Zip codes in Elkhart with the highest recorded infant mortality rates are 46514 (11.8 among Hispanics) and 46516 (8.9 among Hispanics). 46516 has an infant mortality rate of 12.1 (3rd highest in the state) (Indiana Department of Health, 2023a).

The blue circles represent the five zip codes listed by survey respondents at all group events where surveys were collected. These events include Health Fairs, Outreach Activities, and Flu Shot Clinics. B, C, and D belong to Concord Township; E, F, and G belong to Elkhart Township; H is in Middlebury Township; and A belongs to Washington Township.

The red circles indicate the additional three zip codes listed only by survey respondents at Flu Shot Clinics

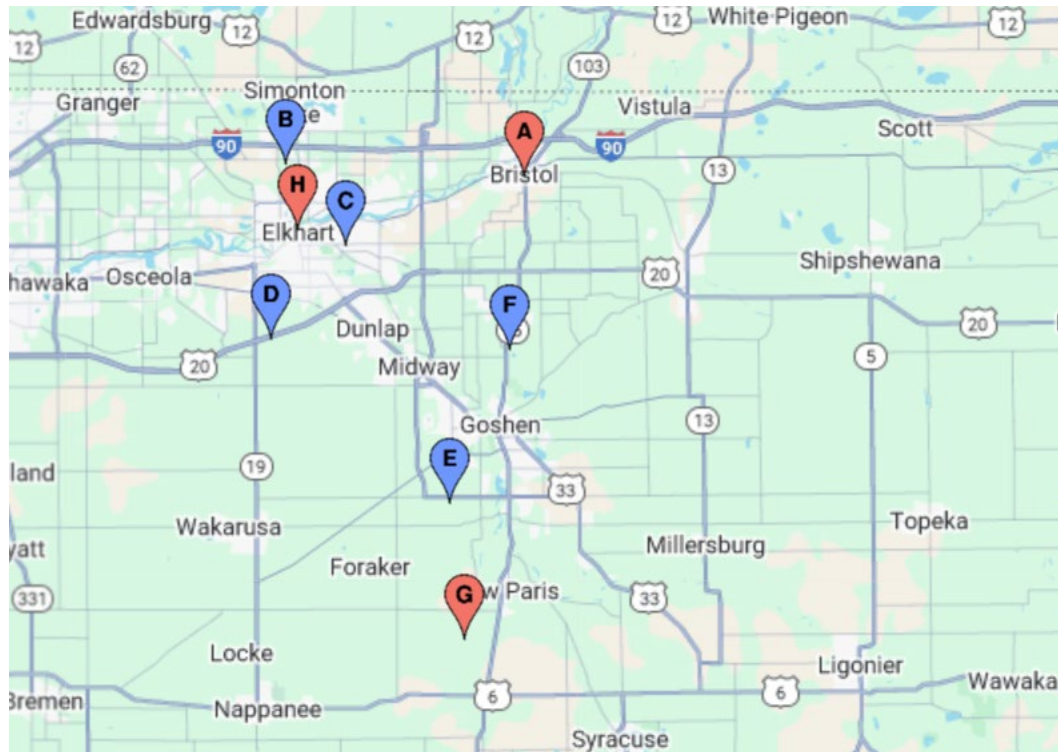
This type of visualization is helpful for:

- Understanding reach: identifying which areas are consistently engaged and which are reached by specialized services.

## From Infant Mortality to Infant Vitality

- Resource allocation: this information helps to decide where to allocate resources or focus outreach efforts.
- Identifying gaps: recognizing areas not reached by all services, which may need more attention.

**Figure 4.** Participation by township and zip code



## LANGUAGE PROFICIENCY

Language proficiency, gender, and age were our most reliable demographic variables. 82% (n=422) of NIHHC respondents had a Spanish language proficiency (i.e. preferred language of communication). Analysis of open-ended responses to question 5 (“If someone told you the highest “infant mortality rate among Hispanics in Indiana is in Elkhart County would you believe it?”) also suggests that community members do not trust race/ethnicity as a reliable measure for health factor prioritization. As figure 7 illustrates, community comments included: “it is not a relation with your race”; “the mortality doesn’t just happen among Hispanics”.

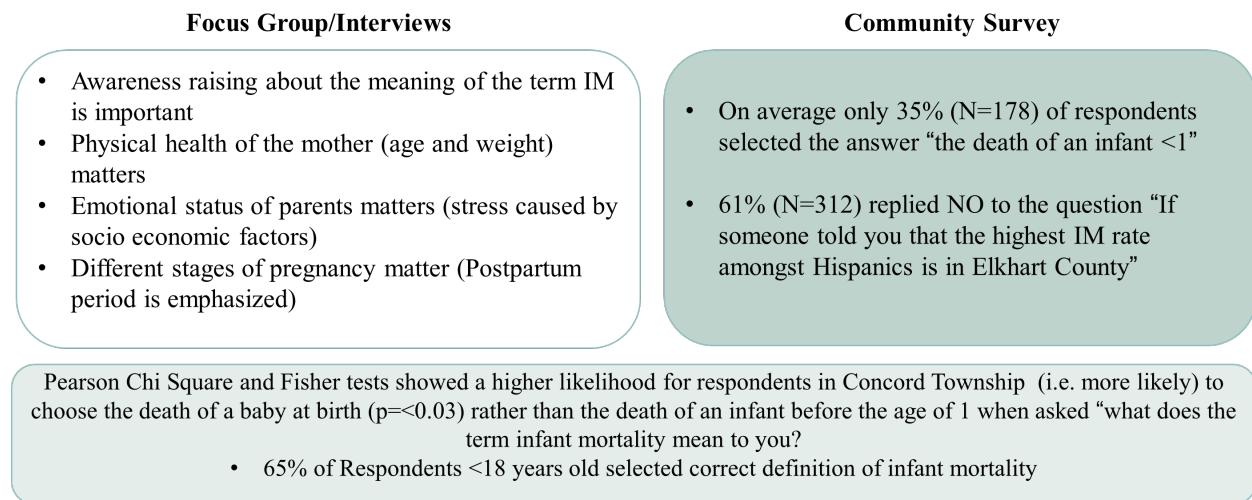
Of note: Language proficiency is a measure which has been successfully used by the Social Vulnerability Index to determine vulnerable populations, this measure is commonly used by NACCHOs (National Association of County and City Health Officials).

## THEMES IN AWARENESS, KNOWLEDGE, AND ATTITUDES TOWARDS PERINATAL HEALTH

In this theme we identify and report on three subthemes: health literacy, knowledge and perceptions of research-identified causes of infant mortality in Elkhart County, and knowledge of available health services. Figure 5 summarizes top-level takeaways based on the team’s analysis and discussion. Takeaways in the left column are those emerging from focus groups and interviews. Takeaways in the right column are those emerging from descriptive and statistical analysis. Descriptive and statistical analysis and evidence for each subtheme are then reported out below in Figure 5.

Of note: The majority of both survey respondents and focus group participants did not know the definition of infant mortality. Descriptive and statistical data analysis suggests some variation by place and age. Analysis of open-ended comments in the surveys analyzed suggests community suspicion of big data demographic categories and low knowledge rates of U.S research identified causes. Focus group data suggests that despite the suspicion of big data narratives, awareness raising about prenatal health is important to the community and that appropriate messaging to improve awareness and knowledge may impact attitudes and behavior.

**Figure 5.** Summary of findings for themes in Awareness, Knowledge, and Attitudes Towards Perinatal Health (quantitative and qualitative)



### HEALTH LITERACY INSIGHTS [Q1] [Q5] [Q6]

**Survey Measure:** The meaning of the term infant mortality (6 options)

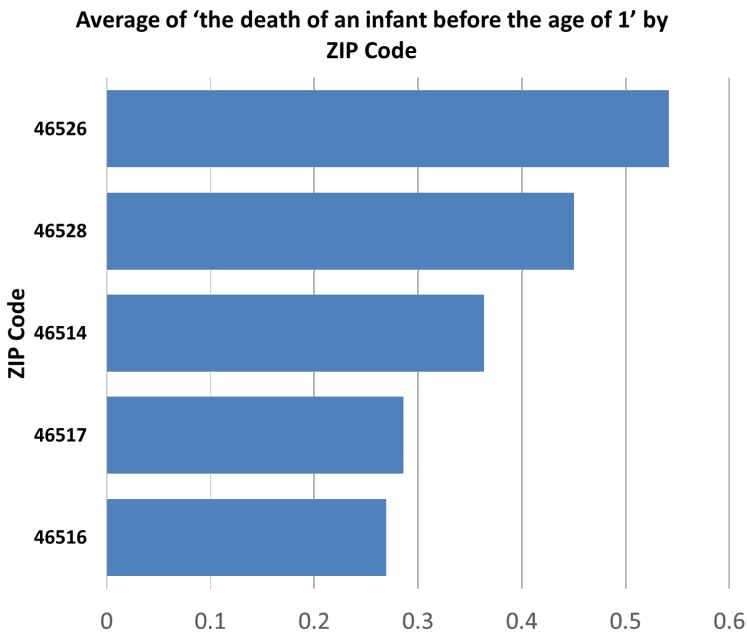
*Q1: What does the term “infant mortality” mean to you? (Mark one)*

The overall average of survey respondents selecting the correct definition of IM is low. Figure 6 and Table 6 show differences in knowledge and understanding of infant mortality by zip code.

Analysis of average values of responses shows that the average value of correct responses (where respondents select the definition of the term infant mortality) is lower in zip codes 46514, 46516, and 46517 than in zip codes 46526 and 46528. While 54% of respondents in 46526 correctly selected “the death of an infant before the age of 1,” only 35% of respondents in all zip codes correctly selected “the death of an infant before the age of 1.”

Additionally, each age group has a similar average score with the exception of those <18 at Goshen High School, where 65% selected the correct definition of infant mortality. Total average scores for all other age groups are below 45%.

**Figure 6.** Selection of ‘the death of an infant before the age of 1’ across zip codes



**Table 6.** Average of ‘the death of an infant before the age of 1’ by zip codes

ZIP Code	Average
46526	0.541666667
46528	0.45
46514	0.363636364
46517	0.285714286
46516	0.269230769
<b>Total Average</b>	<b>0.382049617</b>

Of note: An average score of .38 means that, across the data set analyzed, the average value is 38% of the possible maximum value within the data set.

**Survey Measure:** Belief in the prevalence of infant mortality in Elkhart County

*Q5: If someone told you that the highest infant mortality rate among Hispanics in Indiana is in Elkhart County, would you believe it? (Yes/No)*

*Q6: Why or why not? (Open-ended)*

Analysis of open-ended comments provided in response to Q5 suggests community suspicion of big data demographic categories. The majority (61%; N=312) of survey respondents did not believe the statement that the highest infant mortality rate among Hispanics in Indiana is in Elkhart County, which was true at the time, based on the 2023 report from the Indiana Department of Health (as noted above, current data places Elkhart County 3rd highest for this measure). More women than men did not believe this statement. Figure 7 shows several of the open-ended responses that allow for elaboration on their original response.

**Figure 7.** Open-ended responses elaborating on belief or disbelief in the infant mortality rate in the community



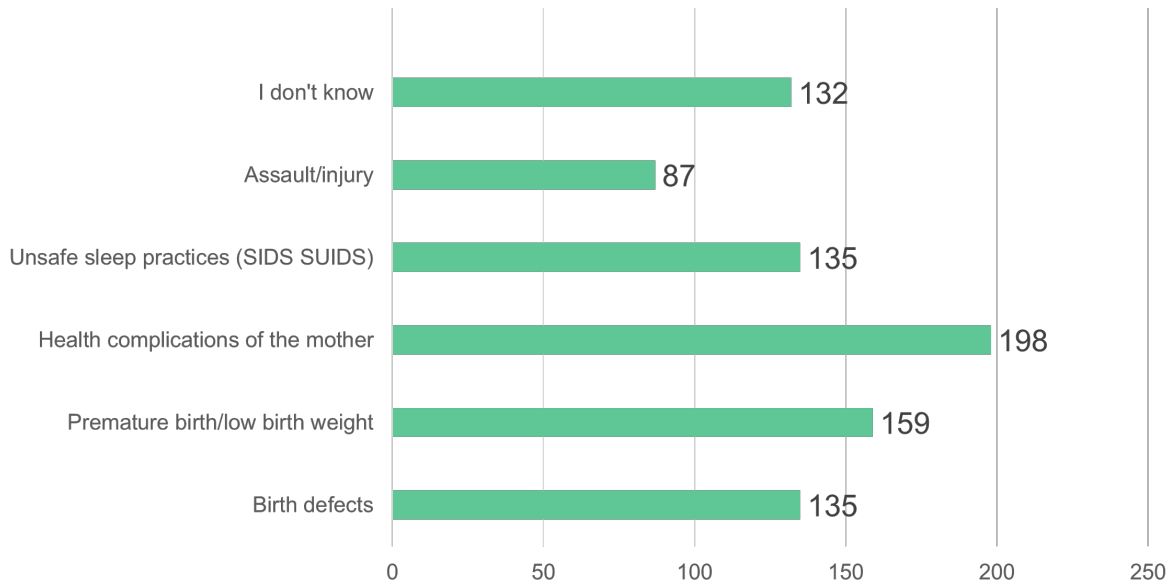
KNOWLEDGE AND PERCEPTIONS OF RESEARCH-IDENTIFIED CAUSES OF INFANT MORTALITY IN ELKHART COUNTY [Q2]

**Survey Measure:** Causes of infant mortality (6 options plus community-identified other)

*Q2: What do you think are the major causes of infant mortality in Elkhart County? (Mark all that apply)*

Figure 8 shows that the survey item, 'Health complications of the mother during pregnancy,' was the one selected by the community as a priority cause of infant mortality (23%; N=198). 'Premature birth/low birth weight' was the second major cause selected by survey respondents (19%; N=159), and 'unsafe sleep practices' and 'birth defects' were selected third (16%; N=135).

**Figure 8.** Causes of infant mortality selected by community members



Of note: Analysis of descriptive data shows that more women (63%) than men selected 'health complications of the mother' as a cause of infant mortality, and that more women (60%) than men selected 'premature birth/low birth weight' as a cause. As Table 7 illustrates, the overall average for respondents identifying premature birth/low birth weight as a cause of infant mortality is very low at 0.28, and averages by zip code vary widely. While 40% of survey respondents in 46528 selected this cause, only 10% of those in 46516 selected it. Also of note is the high number (N=132) of 'I don't know' responses, which suggests that there is room for community knowledge.

**Table 7.** Average of 'premature birth/low birth weight' as a cause of infant mortality selected by community members by zip code

ZIP Code	Average
46514	0.35
46516	0.109090909
46517	0.257142857
46526	0.306451613
46528	0.405405405
<b>Total Average</b>	<b>0.281124498</b>

Of note: An average score of .10 (e.g., see ZIP code 46516) means that across the data set analyzed, the average value is 10% of the possible maximum value within the data set.

KNOWLEDGE OF AVAILABLE HEALTH SERVICES [Q10], [Q11]

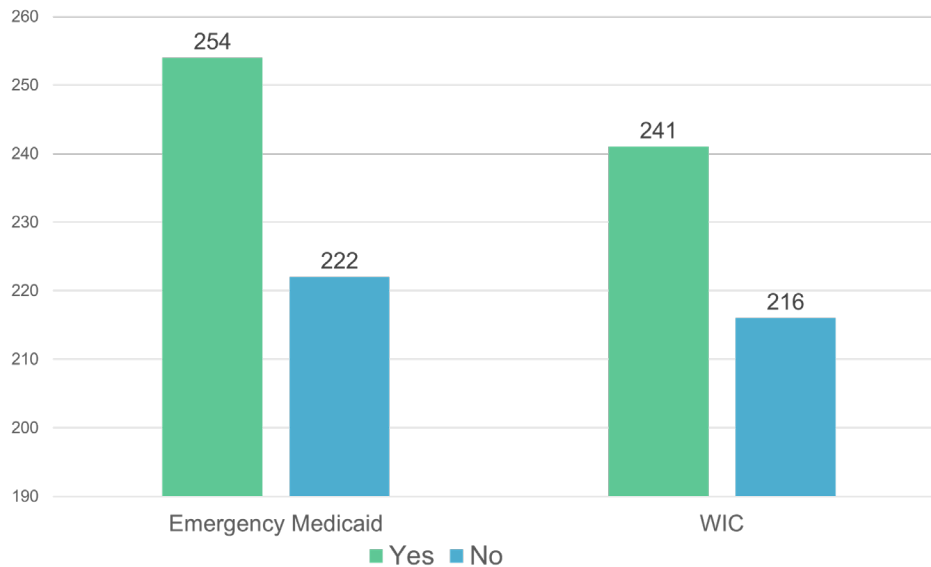
**Survey Measure:** Knowledge of Emergency Medicaid and the WIC office (2 options)

Q10: Do you know what Emergency Medicaid is? (Yes/No)

Q11: Do you know what the WIC office is? (Yes/No)

For low-income Indiana residents, Emergency Medicaid provides limited health coverage for emergency medical services, such as labor and delivery for pregnant women, to individuals who are not eligible for full Medicaid benefits due to their immigration status. WIC (Special Supplemental Nutrition Program for Women, Infants, and Children) provides free healthy foods, breastfeeding support, nutrition education, and referrals to other services, to support low-income pregnant women, mothers, and children under 5 residing in Indiana, regardless of immigration status. Community members showed low knowledge or awareness of Emergency Medicaid and WIC (Figure 9). Among survey respondents, 44% (N=222) did not know about Emergency Medicaid and 43% (N=216) did not know about WIC services.

**Figure 9.** Knowledge of Emergency Medicaid and the WIC office



Of note: The high incidence of low knowledge or awareness of Emergency Medicaid and WIC is particularly noteworthy in light of two things. Firstly, according to the Center on Budget and Policy Priorities in 2022, only 59.8 percent of eligible people in Indiana participated in WIC. In Indiana, for every 10 births covered by Medicaid in 2023, only 3 pregnant people participated in WIC. Secondly, Q4 survey respondent ratings of nutrition (not enough food) (11%; N=177) and supply (can't afford clothing/baby supplies) (6%; N=97) as concerns suggest a need for these services. Combined (17%; N=274), these factors make nutrition, and baby supplies a priority

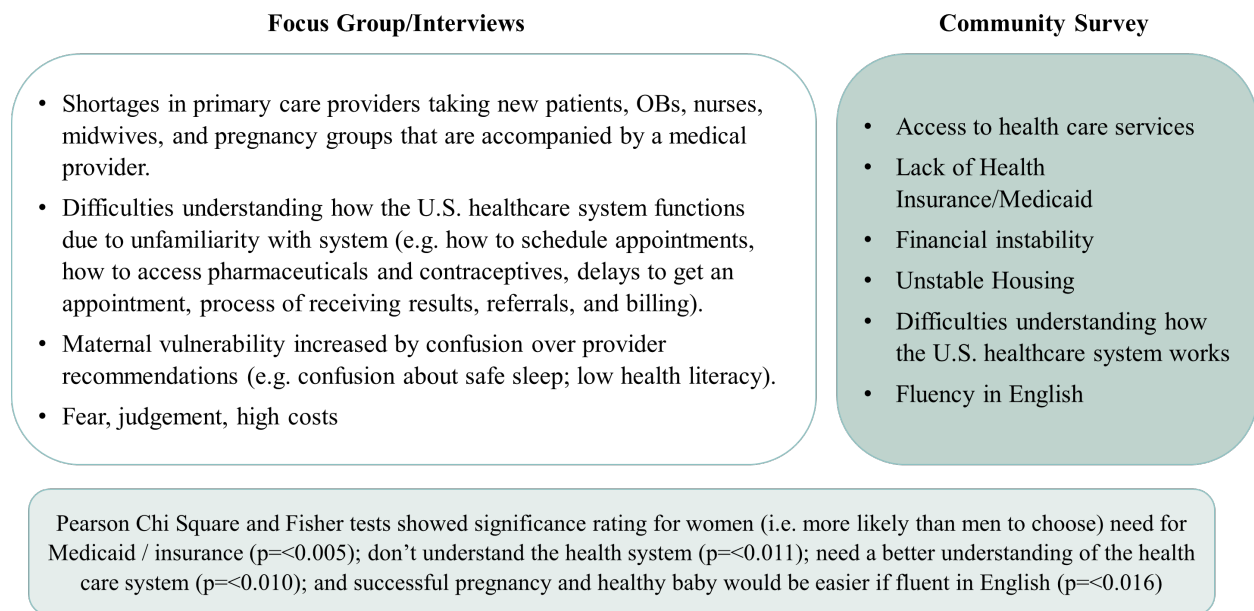
concern, second to not having health insurance/Medicaid (22%; N=355). Finding out why eligible respondents are not using WIC or EM could help to bridge this service barrier.

## THEMES IN BARRIERS TO ACCESSING SERVICES

Researchers estimate that clinical care makes up 20% of the factors that influence health and early childhood outcomes, while health behaviors make up 30%, and the remaining 50% are due to demographic, socioeconomic, and physical environmental characteristics (Health Policy Institute of Ohio). In theme 3, we identify and report on two subthemes: Social drivers of health (SDOH) impacting pregnancy and baby, and Satisfaction with health services used in Elkhart County.

Figure 10 summarizes top-level takeaways based on the study team’s analysis and discussion. Takeaways in the left column are those emerging from focus groups and interviews. Takeaways in the right column are those emerging from descriptive and statistical analysis. Descriptive and statistical analysis and evidence for each subtheme are then reported out below in Figure 9.

**Figure 10.** Summary of Barriers to Accessing Services (quantitative and qualitative)



Of note: The majority of both survey respondents and focus group participants identified better understanding of the U.S. health care system as a potential modifying factor for infant mortality. Descriptive and statistical data analysis suggests some variation by gender, with more women than men selecting better understanding of the health care system as a need and the role language proficiency can play. Focus group data provides additional invaluable insight into the messaging required and barriers to effective communication.

SOCIAL DRIVERS OF HEALTH IMPACTING PREGNANCY AND BABY [Q4, Q7]

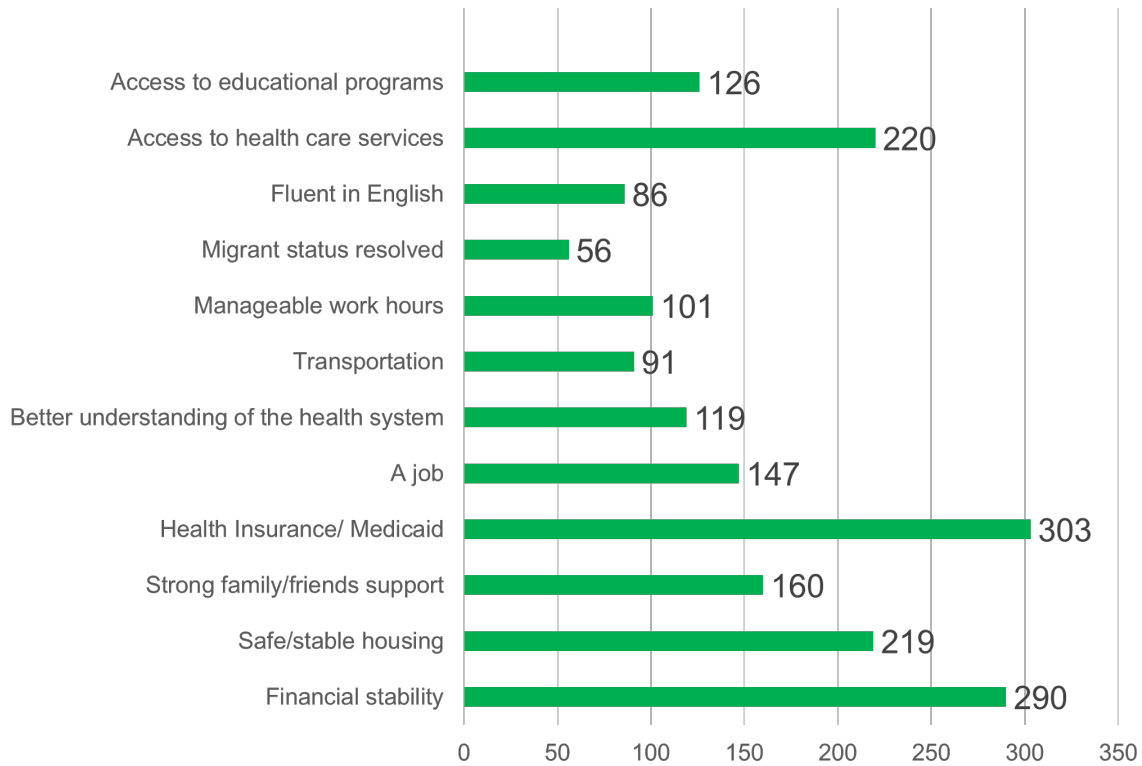
**Survey Measure:** Social Drivers of Health (12 options)

*Q7: For a successful pregnancy and healthy baby, my life would be easier with \_\_\_\_\_ (Mark all that apply)*

Social drivers of health that influence birth outcomes are tied not just to the moment of birth, but also to prenatal care and the health and well-being of the mother before, during, and immediately after pregnancy.

Figure 11 shows that ‘Health Insurance/Medicaid’ was the most frequently selected factor the community deemed necessary for a successful pregnancy. In addition, survey respondents selected financial stability and safe/stable housing as other core factors. This is noteworthy given that the majority of respondents were employed.

**Figure 11.** Social drivers of health impacting pregnancy selected by community members

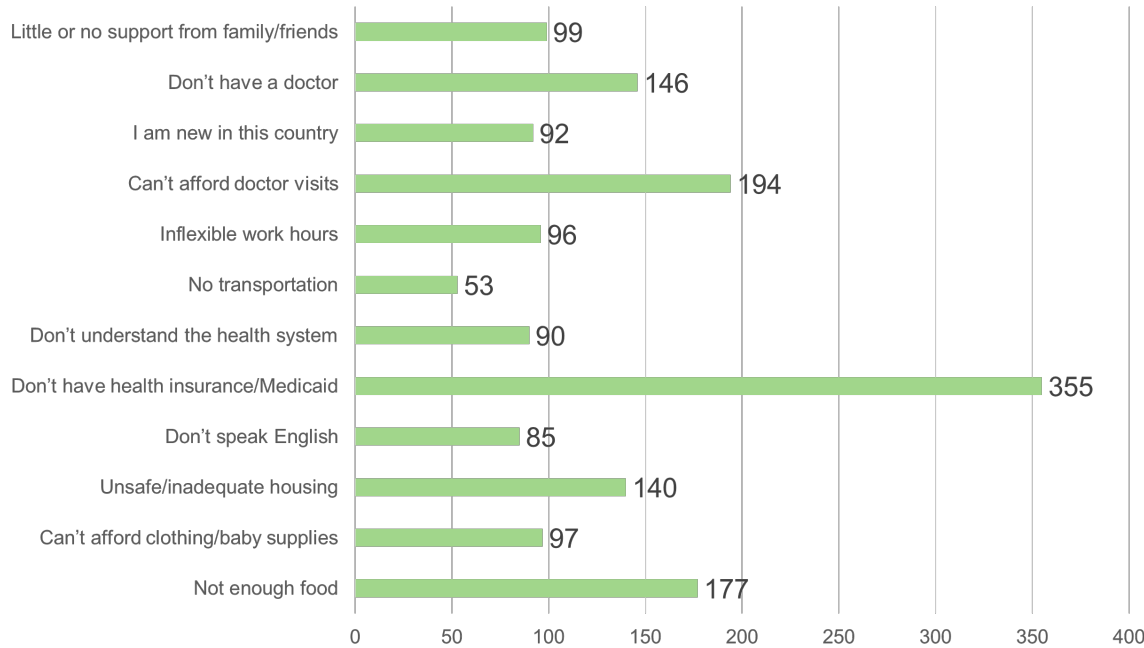


*Q4: When I think about taking care of a baby and/or keeping them safe in this country and especially in Indiana, my main concerns are \_\_\_\_\_ (Mark all that apply)*

Figure 12 illustrates how, of the 12 social drivers of health with the potential to impact infant safety, ‘Don’t have health insurance/Medicaid’ was overwhelmingly the biggest concern for

community participants (22%; N=355). ‘Can’t afford doctor visits’ (12%; N=194) and ‘don’t have a doctor’ (9%; N=146) also scored highly.

**Figure 12.** Social drivers of health impacting infant safety selected by community members

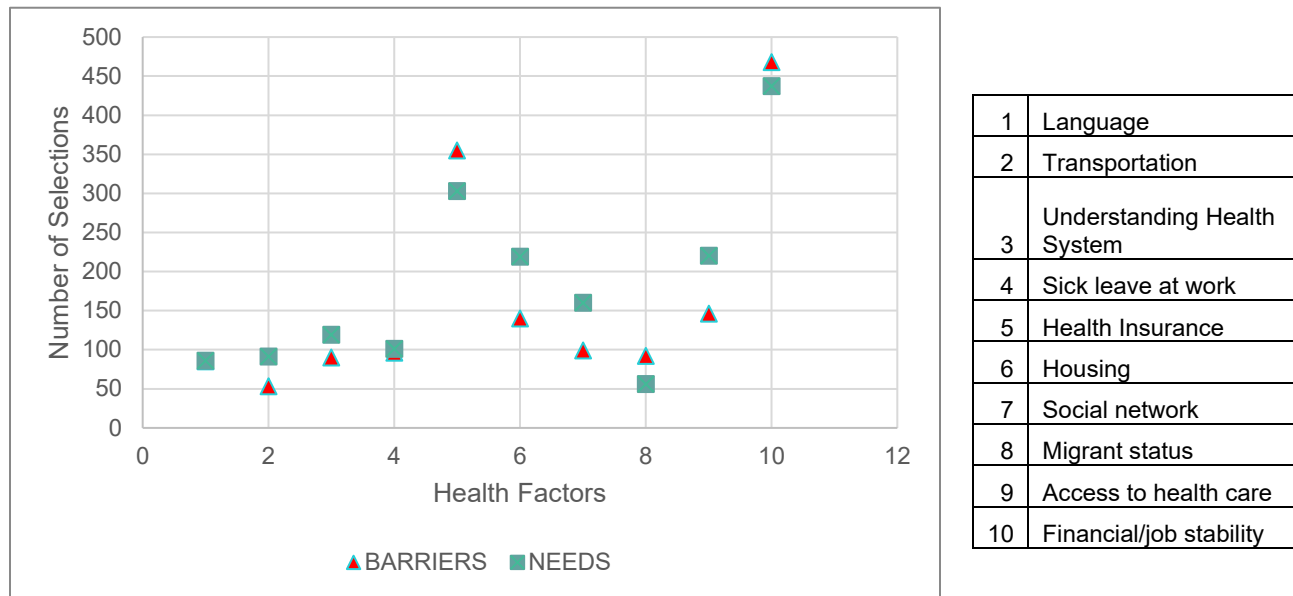


Of note: Based on answers for Q4 and Q7, female respondents placed more significance than men on a good understanding of all aspects of the health system for successful pregnancy.

Pearson Chi Square and Fisher tests showed significance rating for women (i.e. more likely than men to choose) need for Medicaid / insurance ( $p < 0.005$ ); don't understand the health system ( $p < 0.011$ ); need a better understanding of the health care system ( $p < 0.010$ ) and successful pregnancy and healthy baby would be easier if fluent in English ( $p < 0.016$ ).

The following scatter plot (Figure 13) further illustrates the relationships between community concerns/barriers (Q4) and needs of birthers (Q7).

**Figure 13.** Scatter plot of priority concerns/barriers (Q4) vs. needs (Q7) selected by survey respondents



When financial and job security factors are combined for analysis, income and costs are clearly the top concern and need, closely followed by health insurance.

Of note: Comparing answers from Q4 (priorities/barriers) and Q7 (needs), we found that understanding the U.S. health system weights (6%) as a priority vs. (6%) as need, language weights (5%) as a priority vs. (5%) as a need; transportation weights (3%) as a priority vs. (5%) as a need; and social support weights (6%) as a priority vs. 8% as a need. These barriers are correlated and have a significant impact on well-being and should be mitigated, but immigrants often arrive prepared to overcome them, with the support of their informal network/social support. What is less expected, however, is lack of access to an essential public or human need such as health insurance or a job. [‘Don’t have health insurance/Medicaid’ and ‘don’t have a doctor’ are a priority (31%) vs. need (28%), and ‘financial/job stability’ is a priority (28%) vs. need (23%).]

Specifically for transportation, triangulation of survey and focus group responses from health providers suggests that transportation may be an area of misunderstanding between consumers and health providers. Health care providers link missed appointments to lack of transportation: “The lack of transportation has always been a barrier”; “We hear a lot of ‘I could not make it to my appointment because I did not have anyone to drive me here,’ and ‘My husband gets off of work late, and I could not come.’” These testimonials support the interpretation that transportation is another variable that immigrants are expected to overcome with the support of their informal network.

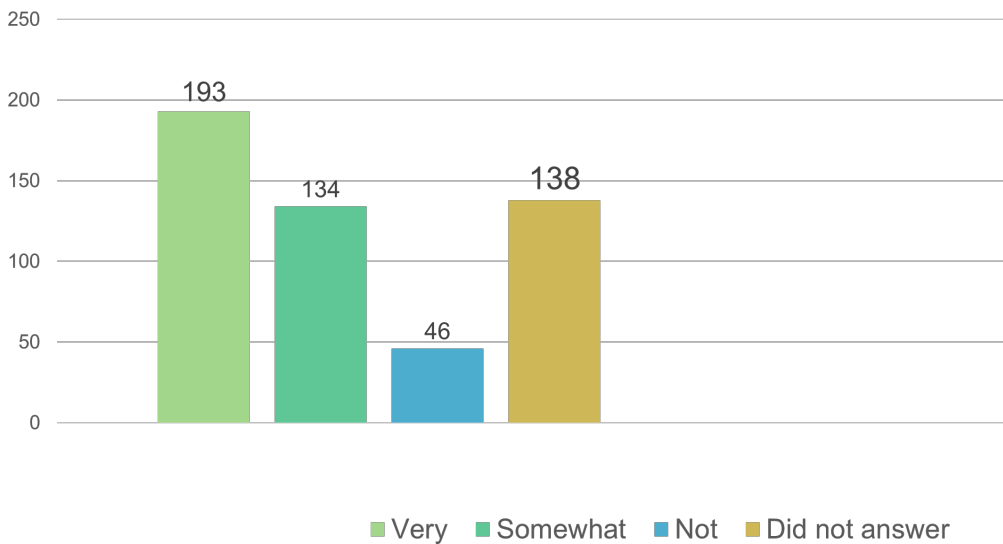
SATISFACTION WITH HEALTH SERVICES USED IN ELKHART COUNTY [Q12], [Q14], [Q15]

**Survey Measure:** Level of satisfaction with healthcare services received (3 options)

*Q12: How satisfied are you with the health care services you have received in the Elkhart County Area? (Mark one: 3 = very satisfied, 1 = not satisfied at all)*

When health services in Elkhart County are accessed, community satisfaction ratings are positive. Figure 14 illustrates survey respondents' satisfaction with general health services they have accessed in Elkhart County.

**Figure 14.** Satisfaction with healthcare services received in Elkhart County



Of note: the high number of non-responses to questions about satisfaction with health services, 27% of respondents did not answer (N= 138) suggests these ratings should be treated with some caution as they may indicate that many survey respondents have not received/experienced health care services.

There is no significant difference between the three survey groupings (health fairs, flu shot clinics and outreach activities). 43% of respondents reached via health fairs (N= 70) were very satisfied with services received; 37% (N=96) reached at flu shot clinics, and 30 % (N=27) during outreach activities.

**Survey Measure:** Anticipated comfort level accessing providers (7 options)

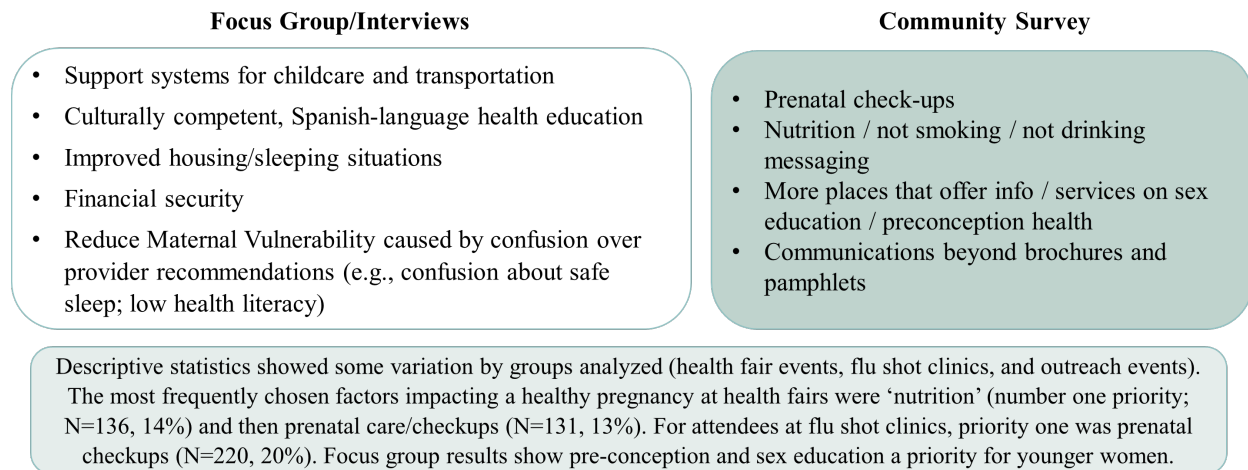
*Q14: If you or your partner were expecting a baby, where would you feel comfortable receiving prenatal care services? (Mark all that apply)*

*Q15: Why would you choose this provider? (Open-ended)*



Figure 16 summarizes top level takeaways based on the team’s analysis and discussion of these descriptive statistics. Takeaways in the left column are those emerging from focus group and interview. Takeaways in the right column are those emerging from descriptive and statistical analysis. Descriptive and statistical analysis and evidence for each subtheme is then reported out below Figure 16.

**Figure 16.** Summary of needs and gaps (quantitative and qualitative)



Of note: The majority of both survey respondents and focus group participants identified culturally competent Spanish language health education and messaging around a range of issues, including nutrition, smoking, drinking, prenatal checkups, safe sleep, and housing. Descriptive and statistical data analysis suggests some variation between groups. The most relevant factors impacting a healthy pregnancy selected by attendees at health fairs were ‘nutrition’ as number one and ‘prenatal care/regular checkups during pregnancy’ as number two. The data collected during flu shot events showed ‘prenatal care/regular checkups during pregnancy’ as a priority, followed by ‘not smoking’ and ‘not drinking.’ These differences suggest added value in matching messaging to audiences. Anecdotally, for example, we know that factory workers attending flu shot clinics are more likely to smoke than those attending high school and church health fairs.

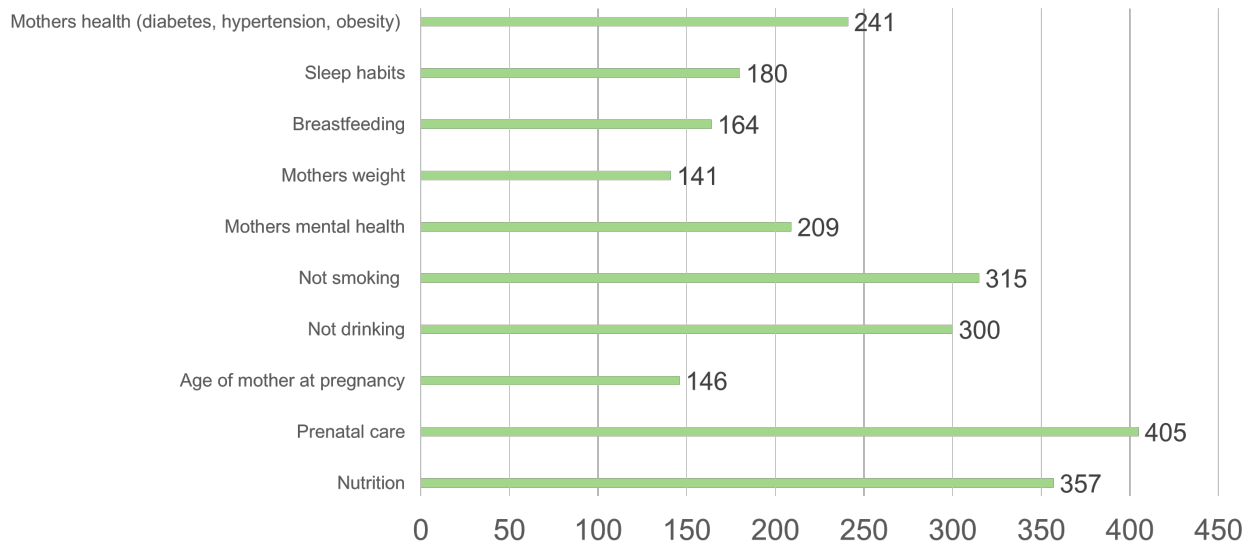
**HEALTH BEHAVIORS IMPACTING HEALTHY PREGNANCY/BABY [Q3], [Q4]**

**Survey Measure:** Health Factors (10 options)

*Q3: For a healthy pregnancy and baby, we need to think about\_\_\_\_\_. (Mark all that apply)*

Prenatal care/regular checkups during pregnancy was selected as the number one health factor impacting a healthy pregnancy and baby by survey respondents (Figure 17). Survey respondents (N=405) chose this option 17% of the time. The second most selected factor was nutrition (15%; N=357), followed by ‘not smoking’ (13%; N=315) and ‘not drinking’ (12%; N=300). Figure 17 shows the health factors impacting a healthy pregnancy and baby.

**Figure 17. Health factors impacting a healthy pregnancy and baby selected by community members**



Of note: Descriptive and statistical data analysis suggests some variation between the groups analyzed. The most relevant factors impacting a healthy pregnancy selected by attendees at health fairs, for example, were ‘nutrition’ as number one and ‘prenatal care/regular checkups during pregnancy’ as number two. These differences show added value in matching messaging to audiences.

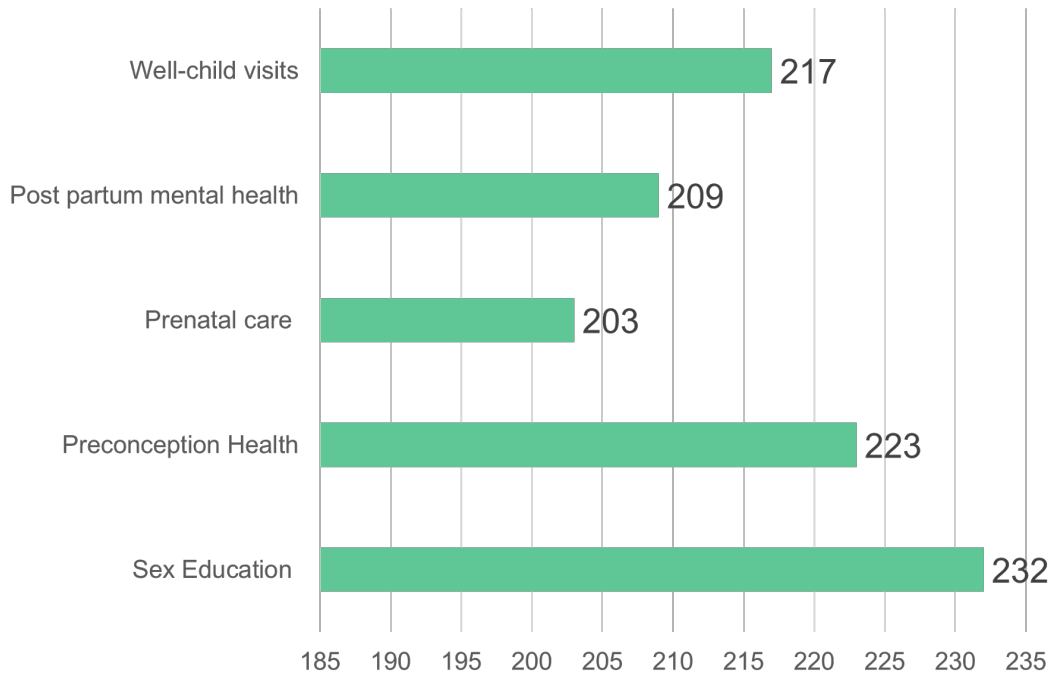
**INFORMATION AND SERVICES NEEDED [Q8]**

**Survey Measure: Perinatal Health Topics (5 options)**

*Q8: I think in this area (Elkhart County), we need more places that offer information/services on the following topics: (Mark all that apply)*

Community members who completed the survey were asked to prioritize perinatal health topics that community members believe require more information or services in Elkhart County. Approximately 40% of the responses indicated the need for pre-pregnancy information. Figure 18 shows the perinatal health topics that community members identified.

**Figure 18.** *Perinatal health topics selected by community members for more information or services needed*



Of note: The finding that sex education and preconception health were priority needs for the community is reinforced by focus group participants. Young women, in particular, commented on the lack of appropriate sex education and education about reproductive health. They appreciated help from WIC, Women’s Care Center, and Healthy Babies and expressed a need for a list of resources and providers that they could tap into during their pregnancy and in the postpartum period.

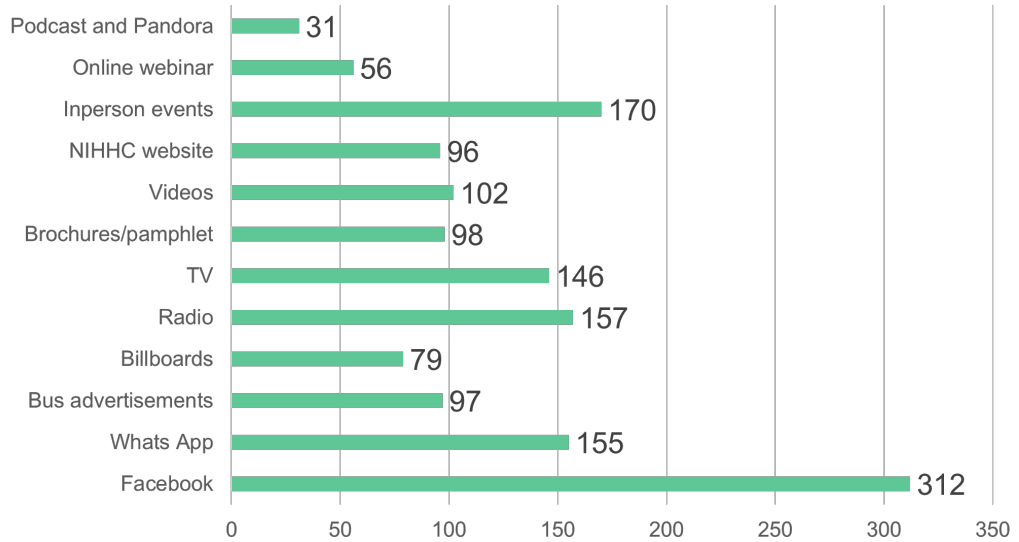
**COMMUNICATION CHANNELS NEEDED FOR PREVENTION HEALTH CAMPAIGNS [Q9]**

**Survey Measure:** Communication Channels (13 options)

*Q9: What communication channels do you think would be more appealing to the Hispanic community to promote preventative health campaigns (such as Infant Mortality)? (Mark all that apply)*

Figure 19 shows the most appealing communication channels in the Hispanic community in Elkhart County. Facebook was overwhelmingly selected as the most appealing channel to the Hispanic community, with 21% (N=312) of survey responses indicating the social media platform. This was followed by in-person education events (11%; N=170) and various digital media, including Hispanic radio, TV, WhatsApp, and videos.

**Figure 19.** *Appealing communication channels selected by community members for a health campaign*



Of note: Combined, billboards and bus advertisements (N=176) are as highly rated to promote prevention campaigns as in-person events (N=170). The key takeaway from the focus groups is that messaging should be culturally relevant, available in the language of preference, and resonate with Hispanic audiences.

#### APPLICATION OF RESULTS TO THE SOCIO-ECOLOGICAL MODEL

We map the qualitative and quantitative barriers identified in the results onto the socio-ecological model (SEM) to illustrate the multilayered and interconnected nature of infant mortality and poor birth outcomes (Figure 20). The SEM is a theory-based framework useful to understand the multifaceted personal and environmental influences on behavior. The model can encourage an expanded view of the causes of infant mortality by moving beyond personal factors to broader interpersonal, institutional, cultural, and political influences. It can assist professionals with understanding the area in which they are positioned to intervene and help them collaborate on implementing multi-level interventions. In Table 8, our main barriers identified are mapped onto the following levels of the SEM: individual, interpersonal, organizational, community, and policy. Holistically and comprehensively providing support to families will require significant effort throughout all sectors of society as opposed to isolated, siloed interventions.

Figure 20. An illustration of the Socio-Ecological Model (SEM)



Table 8. Barriers identified in the study results mapped onto the Socio-Ecological Model (SEM)

Socio-Ecological Model: Level	Socio-Ecological Model: Level Description	Barriers that increase the risk of infant mortality
Individual	An individual's demographic information has the capacity to influence health outcomes, including an individual's gender, religion, race, ethnicity, age, socioeconomic status, and sexual orientation. Additionally, an individual's attitudes, beliefs, behaviors, and level of knowledge shape their health status.	<ul style="list-style-type: none"> <li>- Fear of reaching out for help</li> <li>- Low levels of health education/health literacy</li> <li>- Lack of knowledge or incorrect expectations on how to access the medical system</li> <li>- Poor diet</li> <li>- Time management to cook healthy food</li> </ul>
Interpersonal	An individual's formal and informal relationships are determining factors of health status. These may include family, peer, and patient-provider relationships.	<ul style="list-style-type: none"> <li>- Lack of support system for childcare</li> <li>- Lack of ability to communicate in English</li> <li>- Social isolation</li> </ul>
Organizational/ Institutional	Institutions have the power to shape individuals' behaviors and attitudes, thereby contributing to health status, due to organizational characteristics, regulations, rules, operations, and cultural expectations within the institution.	<ul style="list-style-type: none"> <li>- Lack of medical providers</li> <li>- Lack of Spanish speaking providers</li> <li>- Lack of home visits</li> <li>- Failure to be seen early enough in prenatal care</li> </ul>
Community/ Structural	The environment around individuals influences health behavior and health status. The community environment includes norms, access to resources, and the built environment, including	<ul style="list-style-type: none"> <li>- Poor or complicated referral systems</li> <li>- Housing costs leading to inadequate sleeping conditions</li> <li>- Low wages and late/long hours of employment</li> <li>- Perception of discrimination/ stigma</li> <li>- Cultural beliefs</li> </ul>

	buildings, parks, greenspace, and city-wide infrastructure.	<ul style="list-style-type: none"> <li>- Information/ services needed</li> <li>- Lack of culturally competent, Spanish-speaking health education</li> </ul>
Public Policy	Laws, policies, and allocation of funding are instrumental in determining health outcomes.	<ul style="list-style-type: none"> <li>- Cost of lab work and prenatal care visits</li> <li>- Undocumented status</li> <li>- Lack of healthcare benefits</li> <li>- Limitations of Emergency Medicaid</li> </ul>

Note: Adapted from “Barriers to help-seeking for postpartum depression mapped onto the socio-ecological model and recommendations to address barriers” by J. M. S. Place, K. Renbarger, K. Van De Griend, M. Guinn, C. Wheatley, & O. Holmes, 2024, *Frontiers in global women’s health*, 5, 1335431.

## RECOMMENDATIONS AND DISCUSSION

The following action-items are recommendations, embedded in the broader literature base, to address the concerns brought up in the qualitative and quantitative results and expand across all levels of the socio-ecological model.

### INSTITUTE THE *PROMOTORAS DE SALUD* MODEL

*Promotoras* are trusted community members in Spanish-speaking communities who have insight into local health and social issues and utilize their specialized knowledge to provide relevant and tailored health education and information to their peers in a culturally appropriate way, promoting healthy living and building the capacity of Hispanics to access resources and make informed decisions about complex health issues (May, Kash, & Contreras, 2005). Although often referred to as community health workers (CHWs), community resource navigators (CRNs), maternal care coordinators (MCCs), and other names, *promotoras* typically share common ethnicity, sociocultural values, language, and life experiences with and reside in the community they serve. Under the umbrella specialty of a health paraprofessional, they are subspecialists. Their strong cultural connections enable them to effectively engage with Hispanic communities with compassion, empathy, and a nuanced understanding of their particular circumstances.

The *Promotoras de Salud* model serves as an effective mechanism for engaging Hispanic communities on various health issues, highlighting the significant impact that a bilingual and bicultural care coordinator can have in enhancing health outcomes. The model originated in Latin America through a grassroots movement in the 1960s and was introduced in the U.S. through the Federal Migrant Health Act of 1962 and the Economic Opportunity Act of 1964 (Perez and Martinez, 2008). Since then, it has been established in states throughout the country and evolved to include advocacy, outreach, and support for behavioral change, in addition to health education. Their unique ability to bridge the gap between communities, essential resources, and formal healthcare systems makes them key advocates for health education and outreach in U.S. Hispanic communities (Messias et al., 2013).

In pregnancy contexts, the *Promotora's* direct interactions with expectant mothers and their families, as well as with healthcare providers, position them as effective intermediaries and

messengers. Their strong cultural ties with the communities foster social support and trust, which are critical to addressing the social determinants of health that may hinder successful outcomes such as a healthy pregnancy and delivery. A study by Flores et al. (2017), for example, demonstrated the success of the Promotora de Salud model in promoting folic acid education and increasing prenatal vitamin intake among Hispanic women in four U.S. counties with significant Hispanic populations. The research underscored the crucial role of Promotoras in raising awareness about and facilitating access to prenatal vitamins.

Instituting the Promotoras de Salud model within healthcare systems ensures both a structured training program that empowers Promotoras to successfully conduct their work and a consistent, evidence-based process for healthcare professionals to follow in order to meet the needs of Hispanic patients. The following selected recommendations, based on our study, highlight where Promotoras play a key role in healthcare settings.

### ADDRESS LANGUAGE BARRIERS WITH TRUSTWORTHY MESSENGERS.

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The need for Spanish-speaking employees in healthcare settings frequently arose throughout our study. When discussing effective communication methods and channels, focus group participants identified direct communication as the second most preferred communication method (11%). As trustworthy messengers with knowledge of the local language and culture, Promotoras most effectively address language barriers. They can develop relationships with individual patients to provide accessible and direct communication and follow-up. Promotoras may be more impactful in working under the direction of community-based organizations that already have a long-term trustworthy relationship with the Hispanic community. Once the relationship with the prenatal/postpartum client is established, the specific role of the Promotora includes:

- a. Deliver culturally relevant and accurate health education, and bridge the gap between community members, health experts, and essential social services available in the area (Aboubaker et al., 2014).
- b. Listen to patients' concerns and provide an additional layer of education, including a referral program and follow-up that healthcare providers may not be able to offer due to constraints such as time, language, or other barriers.
- c. Make follow-up phone calls and provide a contact number for further inquiries. This enhances patients' commitment to applying the concepts they have learned and acting on health recommendations, fostering trust between providers and patients.
- d. Once trust is built with the patient, offer regular in-person educational sessions through home visits or after perinatal care visits at providers' offices. These one-on-one meetings can improve community knowledge related to prenatal care, maternal mental health, and infant safety practices.
- e. Address barriers, such as lack of technological proficiency or others related to social drivers of health.

### INFORM AND EDUCATE PATIENTS EARLY ON ABOUT HOW THE HEALTHCARE SYSTEM WORKS IN THE U.S.

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Participants in focus groups highlighted the considerable challenges they face when navigating the U.S. healthcare system, noting numerous inconsistencies compared to the systems they are accustomed to in their home countries. Survey participants indicated that while understanding the U.S. healthcare system is a relatively lower concern (6%) and need (6%), it remains significant. Immigrants expect to experience certain barriers that are naturally associated with acculturation and adaptation to life in a new country, especially when they also face financial insecurity. Barriers, such as language, transportation, and understanding how the healthcare system works, have a significant impact on well-being and should be addressed, but immigrants often arrive prepared to overcome them, often with the support of their informal networks. What is less expected, however, is lack of access to an essential public or human need such as healthcare due to an incredibly complex system.

Promotoras are crucial to making the connection between understanding the system and accessing affordable and quality healthcare. They are necessary for providing culturally competent education to effectively learn how to navigate the healthcare system and address associated challenges, such as financial obstacles. For instance, part of learning is to know how the healthcare system works related to billing. Patients should be prepared to receive multiple bills for a single doctor's visit (including charges from the doctor, facility, radiology, labs, etc.).

### EDUCATE WOMEN ABOUT THEIR ELIGIBILITY FOR VARIOUS OB/GYN SERVICES.

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In some countries, ultrasounds are performed at every other appointment, whereas in Indiana, patients are restricted to 2-3 ultrasounds during a typical pregnancy. The limited access to ultrasounds has been a common source of frustration and anxiety in focus groups, as these procedures are vital for many women to bond with their fetus during pregnancy. The lack of explanation for denying this service can influence a pregnant woman's trust in her doctor or discourage her from continuing to attend doctor appointments. This information, along with other eligible services, can be effectively communicated through Promotoras, so that patients know what to expect.

### INCREASE AWARENESS-RAISING AND HEALTH LITERACY RELATED TO INFANT MORTALITY

Demographic characteristics of community members who participated in our study show a low level of education and a strong language preference for Spanish. Among focus group participants, 67% have a GED or lower level of education. Regarding language proficiency, 83% of both focus group participants and survey respondents selected Spanish as their preferred language. Low literacy levels combined with low English levels suggest that the ability to access, understand, and use health information and services to make informed decisions about one's health and well-being is limited without the careful consideration of the unique needs of the population.

In addition, the high percentage (57%) of survey respondents who do not know the causes of infant mortality suggests that in-depth education is needed. Community members in focus groups expressed a lack of understanding of health conditions related to pregnancy and birth

outcomes and inadequate educational materials, whether due to poor translation, inappropriate literacy level, or a lack of comprehensible explanation or instruction. Providers in interviews recognized that patients may lack understanding of medical conditions, whether due to lack of culturally appropriate explanation or a patient's level of education.

The education level of parents is often related to a child's life expectancy. For each year of a child's life, both parental and maternal education are key for prolonging a child's life expectancy (Balaj et al., 2021). The average reduction in risk of a child dying in their first 5 years of life for a mother with 12 years of education compared to one with 0 years of education is 31% (Balaj et al.). Thus, low parental education levels are risk factors for child mortality, and increasing education levels of both expectant mothers and fathers is an important policy-level strategy to reduce infant mortality.

Furthermore, the level of health literacy is essential when looking at the life expectancy of a child. Lee et al. (2018) examined how maternal health literacy impacts early parenting practices among low-income and low-English proficiency mothers at federally qualified health centers in an urban county in central Texas. Their study demonstrated that mothers with adequate health literacy had better self-efficacy compared with mothers with inadequate health literacy. Lee et al. also identified ethnic minority status and low education levels as having a significant correlation with a lower level of health literacy. Providers who work with parents with low education levels, low health literacy, and/or low English proficiency must recognize the intersection of these risk factors and the increased need for awareness-raising and health literacy on specific topics.

### RAISE AWARENESS OF INFANT MORTALITY AS A FIRST STEP.

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Our study found that a high percentage of community members (90% among focus groups and 68% among survey respondents) are not aware of infant mortality, including its meaning, prevalence, and the contributing factors. The low average scores by age group (below 45% except for those younger than 18) for selecting the correct definition of "infant mortality" suggest that understanding of this term is primarily driven by community knowledge rather than formal education, and that a community-wide prevention campaign is required. Further, 62% of survey respondents did not believe that Elkhart County has one of the highest rates of infant mortality among Hispanics. Raising awareness is a critical first step toward increasing understanding of infant mortality and potentially influencing attitudes, behaviors, or beliefs to prevent it.

Furthermore, providing Hispanics with key facts about infant mortality in the local environment where they live and specifically where it is needed most will empower them to actively become part of the solution by promoting better perinatal health within their community. While 54% of survey respondents from 46526 knew the correct definition of infant mortality, only 32% of the respondents from zip codes 46514 and 46516 selected the correct definition. As noted previously, the latter two zip codes have among the top ten highest rates of infant mortality by zip code in the state of Indiana. Efforts to improve health literacy on infant mortality should be focused on these zip codes.

### RECOGNIZE THAT HEALTH CONCEPTS ARE CONTEXT DEPENDENT.

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Beyond raising awareness of concepts such as high infant mortality, providers must ensure that patients and community members have an accurate understanding of what such terms mean in the context of their care in the U.S. Education level is not necessarily associated with knowledge level. Based on their own experience, culture, and learning environment, community members may already have a strong knowledge base of the topic, which may or may not be congruous with the provider's. For example, in some Hispanic countries and in many other parts of the world, there is greater focus on under-five child mortality (the death of a child before their fifth birthday), which sometimes becomes synonymous with infant mortality. Further, community members in our study noted an immediate association of the term "mortality" with "death," which shifted their focus to an almost helpless sense of morbidity, fear, and danger rather than an empowered sense of agency in the forward steps they can take and the healthy behaviors they can do to ensure vitality and a healthy future for their baby.

### FOCUS ON CULTURALLY SPECIFIC AND IN-DEPTH EDUCATION RELATED TO INFANT MORTALITY.

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Providing specific and in-depth education on infant mortality and related topics is required for effective health literacy. Specific education on concepts that are new to patients may include specific information on infant mortality (meaning of the term), early pregnancy, health conditions associated with high risk (e.g., gestational diabetes, preeclampsia, endometriosis), nutrition, prenatal vitamins, physical activity, safe sleep, warning signs of a sick baby or pregnant mother, safety guidelines, and how and when to access urgent care. In-depth information on high-priority topics is needed specific to the local population.

### SEX EDUCATION

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In our study, sex education was a primary need and a common theme identified through the community focus groups and provider interviews. It was also the most frequently selected (22%) topic by survey respondents for what they need more information on. Thus, special attention should be paid to this health education topic. If women, men, or adolescents are not at an age or stage of life where they want to be raising a child to adulthood, they need the tools and knowledge to be able to plan and effectively implement that plan within their cultural context. Our recommendations include creating and disseminating general, Spanish-language sex and reproductive health education; advocating for comprehensive, medically accurate, Spanish-language sex education; and being frank about sex education, contraception, and how to prevent unplanned or unwanted pregnancies.

There are several factors that impact access to sex education among Hispanics, including communication channels for reproductive education, religious considerations, the role of pediatricians and schools, parent knowledge, and the role of cultural values and family, especially impacting teens. In many Hispanic cultures, it is taboo for parents or other adult family members to discuss sex with their children, which leaves that responsibility to the pediatrician. In a study that examined the perspectives of expecting and parenting Hispanic

adolescents on the factors contributing to teen pregnancy and strategies for its prevention, key themes that emerged included the importance of private time with physicians, mentorship from parenting teens, reproductive health education, and community-based prevention programs Xiao et al. (2023). Participants expressed a strong preference for one-on-one interactions with healthcare providers, especially when confidentiality was assured (Xiao et al.). This emphasizes the need for medical providers to clearly communicate that any information shared during appointments will remain confidential and not be disclosed without authorization.

At the same time, provider communication with parents is also critical for closing the knowledge and trust gap. Providers should explain to accompanying parents the importance of private interactions with adolescent patients to build trust and foster open communication, and they should share the educational talking points with parents. When parents have a clear understanding of the topics discussed, they can be available first-hand to respond to questions, so that children can continue the conversations at home instead of finding answers on their own from unreliable sources. Especially given the core cultural value of *familismo*, emphasizing strong family loyalty, closeness, and interdependence, discussions about sex must involve parents, too, either separately or with the child if possible.

Both male and female participants in the study also reported widespread concerns about the side effects of contraceptives and a general lack of accurate information about the available methods (Xiao et al., 2023). This knowledge gap was largely attributed to factors such as young age, inadequate school-based health education, and limited awareness of available reproductive health services. These findings highlight the imperative need for comprehensive reproductive health education beyond an annual doctor visit that equips adolescents early on with accurate information and accessible resources.

When information is inaccurate or contradicts the religious beliefs of parents, parental trust in the provider may be broken, and parents may stop bringing their children to doctor visits. Thus, strong religious beliefs must also be considered when discussing sex and reproduction in the Hispanic community. In the Catholic religion, the position around reproduction is clear that procreation is a primary purpose of marriage and sexual intercourse; couples should be open to the possibility of procreation. This means that couples are not allowed to use methods of contraception that prevent pregnancy, such as artificial contraception. Given that faith and religion is one of the main cultural pillars of the Hispanic community, it is crucial to have parents involved in the discussion about procreation and contraception. In a study examining the influence of religiosity on pregnancy acceptability among Hispanic young adults, those who considered religion to be an important part of their lives had significantly higher odds of viewing pregnancy as acceptable compared to those for whom religion was less important Rodriguez et al. (2020). These findings highlight the critical need for healthcare providers to recognize how health beliefs influence their patients' behaviors. Teens, in particular, have a complex set of influences and often mixed messages, including acculturation and a generational shift, health classes in school, and religion and family loyalty. Oftentimes, parents may make assumptions about their teens based on cultural values that have lost the same impact as teens adapt to life in the U.S. Thus, parental guidance in navigating these conflicting messages is fundamental for addressing teen behavior.

When offering information on reproductive health services, prenatal care, family planning, and pregnancy prevention, providers should take these beliefs into account to ensure culturally sensitive and effective care. Schools, providers, churches, and adult family members must all recognize their role and position as a connector to help teens navigate sex education.

On the other hand, for women over 35, whose pregnancies are high risk, doctors may caution against getting pregnant. Under these circumstances, Catholic churches often support doctor recommendations, and women can receive the support needed to prevent pregnancy. Conversations around this medical restriction and procreation are not new among priests. Thus, again, it is critical for providers to understand this relationship and make the connection when discussing options with older patients.

### SAFE SLEEP EDUCATION

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Results from the focus groups and interviews underscore the complexity of the safe sleep issue among the Hispanic community in Elkhart County. Safe sleep is emphasized by providers, and a large portion of resources is put toward this kind of education. This is understandable in part because it is a more easily modifiable behavior at the individual level. At the same time, it is often considered a primary cause of infant mortality among Hispanics, when in fact, it is the third highest cause after perinatal risks and congenital abnormalities (Indiana Department of Health, 2023a). Still, SUIDs are preventable and safe sleep education is impactful and necessary. Community members expressed the importance of the safe sleep education they received, albeit sometimes confusing, especially compared to some advice received from their elders. However, it is imperative to address the need for culturally appropriate safe sleep education. Providers should continue to talk often about safe sleep practices while acknowledging cultural traditions and informal family networks, explaining the risks of unsafe sleep practices clearly.

Strategies for safe sleep education must also consider other environmental factors, such as housing and physical space, and not just cultural practices. Thus, some re-evaluation is needed regarding clarity in messaging, appropriate communication channels, and strategies that address viable ways that parents can implement safe sleep practices. Multiple culturally appropriate communication channels and trusted messengers who can ensure community members respond to the education they receive are key. For example, in response to the alarming SUIDs rates, several partners in Cass County, Indiana worked with Purdue University to create the evidence-based, “Why Safe Sleep Matters” educational stories on safe infant sleep practices, available in English, Spanish, and Haitian Creole (Purdue University, n.d.). This innovative approach uses different information sharing channels such as in-home visits, public health departments, workplace televisions, and hospital discharge. The multiplicity in information sharing procedures aims to eliminate the barriers to information access and ensure content relevance for Hispanic and other communities. According to another study that assessed the feasibility, acceptability, and initial outcomes of safe sleep community baby showers for women who speak Spanish (Ahlers-Schmidt et al., 2021), these kinds of events connect pregnant or recently delivered women with perinatal community resources, build social support networks, and allow them to learn about standards of care promoted by the American Academy of Pediatrics (AAP), among other trusted sources of information.

### MEDICAID AND WIC EDUCATION

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Our survey results revealed that nearly half of respondents (47%) did not know about emergency Medicaid or WIC (Special Supplemental Nutrition Program for Women, Infants, and Children), two critical resources for accessing healthcare and healthy behaviors for uninsured and low-income women, suggesting that improving health literacy and marketing educational campaigns should be targeted toward zip codes with high poverty rates where food deserts are present. Even when many community members are eligible to receive these resources and may be aware of them, participation is low. Nationally, for the WIC program, participation is lowest among eligible pregnant women, and even when enrolled, they may not use the benefit (USDA, 2023). Community members need education on how to apply for and use these programs, or if culturally competent resources are available, they must be connected with them.

### USE APPROPRIATE AND EFFECTIVE COMMUNICATION METHODS AND CHANNELS TO PROMOTE AWARENESS AND HEALTH LITERACY.

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Efforts to increase awareness and health literacy will not be successful without effective communication. Providers must seek ways to provide accessible educational tools designed to improve awareness-raising and health literacy. Negative health information-seeking experiences are very common in non-English speaking, low-income populations and those with limited health literacy (Chu et al., 2022). Therefore, healthcare systems and public health departments should consider both language preference and health literacy throughout the process of developing and disseminating health information (Chu et al.). The following recommendations consider the complexity and specificity of communication methods and channels needed to ensure awareness and health literacy among the Hispanic population in Elkhart County.

### ENSURE THAT AWARENESS-RAISING TOOLS, LIKE BROCHURES, ARE CULTURALLY RELEVANT AND RESONATE WITH HISPANIC AUDIENCES.

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Participants in focus groups highlighted that effective communication is crucial for engagement and understanding. They noted that long, written materials in Spanish were often handed out without explanation and met with frustration and disregarded. Even when materials are in Spanish, they may not be appropriate to the literacy, education, or acculturation levels of patients. Healthcare systems should consult with local experts in bicultural–bilingual competencies, such as Promotoras, community-based organizations, or healthcare centers with demonstrated experience working with the local Hispanic population, to assess and create culturally suitable materials. These consultants will be most familiar with the local Latin American diasporas and Spanish language dialects used, and they can also recognize when education level and language proficiency are relevant to accessing information, particularly when presenting a new medical concept in English (e.g., preeclampsia or gestational diabetes), and adapt materials accordingly.

### PROVIDE ONE-ON-ONE EXPLANATIONS IN PERSON TO PATIENTS AND USE DIRECT COMMUNICATION.

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Focus group participants were discouraged by the lack of explanation and time from healthcare providers at appointments, while in-person events was notably the second most preferred communication method among survey respondents. Along with the revision and development of educational material, it is essential for medical providers to incorporate interactive explanations and/or demonstrations during consultations with patients to significantly improve their understanding. Patients with low health literacy may struggle with reading, comprehension, and memory, especially regarding complex medical information, thus explanations need to be given at a very basic level using straightforward language that avoids medical jargon. Such patients face considerable difficulties in navigating healthcare systems, and evidence-based strategies such as patient-centered communication, clear communication techniques, teach-back and teach-to-goal methods, confirmation of understanding, and reinforcement can improve health outcomes (Sudore and Schillinger, 2009).

When initial understanding is fostered through direct and meaningful interaction with a medical provider, the patient-provider relationship is strengthened. Patients feel heard and valued, enhancing their overall care experience. They may feel more at ease voicing their questions or concerns, expressing sentiments such as, 'Now I understand' and 'Could you please explain that again?' This dialogue creates an opportunity to implement these strategies to ensure understanding and retention. Strategies like the teach-back method, which involves asking patients to repeat the information they have been told in their own words, do not necessarily require more time but enhance the quality of communication. Teaching patients about self-care and the U.S. healthcare system through individualized explanation that recognizes their perspectives and utilizes their existing skills and knowledge empowers them to take control of their health.

### USE VISUALS AND GRAPHICS TO SCAFFOLD EXPLANATIONS.

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Rather than avoiding explanation of technical or complex medical concepts, intentional effort should be made to make content comprehensible. Providing information in various formats (written, spoken, and visual) increases comprehension. The lower the English level, combined with a low literacy level, the more providers need to use teaching aids, such as anatomy models, and illustrated hard copies of educational material to support verbal explanation. Providing hard copies of documents in Spanish allows for further review by the patient and empowers them to follow recommendations at home and be better prepared for upcoming visits. For those patients with lower reading skills, however, traditional brochures may not be the best method for supporting explanations. While some patients may be comfortable with written materials, others may require more illustrations or audiovisual aids to better grasp diagnoses or instructions. It is crucial to support explanations with materials that are visually oriented and use less complex vocabulary, tailored to the patient's literacy level.

Focus group feedback reinforced the notion that visual content is more engaging and easier to understand than lengthy written materials or brochures, and participants emphasized using videos as an alternative. Community members showed a positive response to concise dynamic videos. For example, community members might favor multiple short, engaging videos akin to popular TikTok content rather than a single lengthy, conventional video delivering the same

information. These kinds of short videos can be used in providers' offices to scaffold explanations, in addition to other communication channels.

### EMPLOY DIGITAL COMMUNICATION STRATEGIES, ESPECIALLY VIDEOS AND FACEBOOK.

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Facebook and other online platforms are communication modes heavily used and trusted by Hispanics. In our survey, Facebook was the most appealing communication channel by a wide margin, with 80% of respondents choosing the social media platform. Research shows that digital communication strategies (i.e. social media, texting, and mobile apps) used by trusted organizations to promote healthy behaviors among low-income pregnant women and parents of young children are effective, engaging, and accessible, especially when members of the target population (such as Promotoras) are involved in the design of the content (Eppes et al., 2023). It is crucial to use existing effective educational communication channels that are already appealing to Hispanics to spread general health messaging concerning infant mortality. Longer educational videos from reputable sources should be created and disseminated through appealing channels like Facebook, WhatsApp, and radio campaigns among Hispanics. Avenues for presenting educational content can be explored during personal educational sessions with healthcare professionals, at community gatherings featuring expert speakers, and by displaying these videos in waiting areas to raise awareness about infant mortality and promote strategies for safeguarding children's health and well-being. For instance, NIHHC regularly hosts online educational sessions titled 'Pills of Knowledge,' which are available on Facebook and deliver clear, topic-specific information from a health professional. This digital strategy is very popular, and the trusted relationship built with NIHHC increases community members' loyalty to engaging with the material.

### UTILIZE INFORMAL NETWORKS, SUCH AS FAMILY AND FRIENDS, FOR COMMUNICATION PURPOSES.

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Immigrants often depend on these social connections for support, information, and opportunities, particularly when adjusting to new surroundings and seeking resources. During our interviews, providers noted that clients frequently sought health information from their family and friends. A study conducted by Moreno et al. (2024) on Central American pregnant women in the U.S. revealed that women of all ages commonly rely on informal information sources. Thus, providers should involve family members in health awareness initiatives and educational efforts, recognizing their significant role in shaping beliefs. Instead of perceiving these sources as potentially conflicting, providers should invite family members or individuals from a patient's social support network to attend educational events or one-on-one educational sessions. Integrating family members into the patient's health journey by providing them with accurate information can harness local knowledge and foster a well-informed network, equipped with credible information, and potential advocates for making informed healthcare decisions.

## ADVANCE HEALTH INTEGRATION

Participants in our focus groups highlighted the complex challenges associated with being referred to various providers for different medical services during their pregnancies, spanning

from early to late prenatal care and delivery. Research indicates that fragmented care can result in disjointed patient experiences, communication failures, inefficiencies, increased costs, and poor patient outcomes (Pickering & Embry, 2013, p.38). Under a fragmented system, both patients and providers must grapple with a lack of continuity on medical history, elevated costs, intricate billing procedures, patient transportation barriers, and difficulties establishing trusting relationships, among other issues. This situation is exacerbated when patients are facing language, literacy, and cultural barriers. The following recommendations respond to the need for integrated and coordinated care, with respect to both health services and healthcare providers, which can improve the quality of and access to perinatal care.

### PROVIDE MULTILAYERED, “ONE-STOP-SHOP” COMMUNITY-BASED EVENTS.

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At one-stop-shop community-based events, pregnant women who are disparately impacted by structural barriers can access multiple various resources, such as support for accessing health insurance, housing, healthy food, and other necessities, as well as preventive healthcare services and assistance in accessing clinical and government services. This kind of initiative integrates multiple aspects of health, including social drivers of health, to create a more comprehensive and coordinated approach to well-being.

The implementation of a “Family and Pregnancy Pop-Up Village” in San Francisco is an example of successfully providing social, public health, clinical, and wraparound services needed for a healthy pregnancy in one location (Hawkins et al., 2023). The Pregnancy Pop-Up Village disrupts siloed systems by delivering services as a one-stop-shop in an uplifting, welcoming environment and responding to community feedback (Hawkins et al.). It not only brings all services to one location, but also responds to many social drivers of health, such as transportation, lack of interpreters, childcare, health literacy, and healthy food, among others.

Similar initiatives have been successful in the Northern Indiana region. For example, in 2023, St. Joseph County WIC hosted a World Breastfeeding Event at the South Bend Cubs Stadium, where 31 vendors provided education and referrals to managed healthcare organizations with over 475 attendees (Beacon Health System, 2024, p. 15). This demonstrates the effectiveness of holding an event along the lines of healthy pregnancies and infant well-being in a setting similar to Elkhart County.

In Elkhart County, NIHHC has been a leader in running health fairs using a one-stop-shop model. During the COVID-19 pandemic, from July 2021 to December 2023, NIHHC organized 32 outdoor (drive-thru) and indoor vaccination clinics, inviting families to be served in one car or attend together. At all of the clinics, culturally competent, bilingual NIHHC’s Promotoras de Salud were available to provide one-on-one educational outreach, so that attendees could make an informed decision regarding the vaccine or next steps in their healthcare. Brochures written in Spanish at a 4th grade reading level were also available to provide additional educational information. Attendees received food, such as tacos and a drink, as well as gas gift cards, responding to the transportation barrier. NIHHC partnered with public health providers and other community organizations for these events, including the local public library to distribute books for all ages in English and Spanish. In addition, for several of the indoor events, NIHHC offered

preventive health screenings, using a holistic health approach and creating the opportunity for more comprehensive services. This model was so successful that there was a return rate of 85% among attendees between the first, second, and third shots, and more than 3,700 unique individuals were served. This model is easily scalable for any other public health need.

### PROVIDE IN-HOUSE SERVICES WITH MULTIPLE TYPES OF HEALTHCARE PROVIDERS WITHIN ONE HEALTHCARE FACILITY.

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Integrated and coordinated healthcare delivery is a key component of health integration. Clinical care should be integrated with behavioral health care, nutrition, chronic disease management, pregnancy care, dental care, vision care, and social support. Healthcare systems should work to create a multidisciplinary in-house team: navigator to find insurance options; social worker to scout out resources, arrange transportation, and help with financial assistance applications; nutritionist for orientation on healthy diet; Spanish-speaking doula for extra support during labor and delivery; mental health specialist for postpartum depression needs; pharmacist to dispense medications; and Promotoras assigned to the patient to guide them through the services. This integration also helps ensure continuity of care during pregnancy and delivery, leading to improved maternal and infant health outcomes, including fewer complications and higher quality of care. Consistent communication and support from a provider from month 1 to 9 in pregnancy builds trust and enhances overall patient experience and well-being, especially among vulnerable populations.

Clinics should staff mental health professionals within the care team. Referrals for mental health can take place at the earliest signs of struggle with mental health. Social workers can make house calls or check-ins for women in the postpartum period, and nurses can make regular, planned home visits in the postpartum period to provide education and support about newborn care, schedule follow-up medical care for baby and mom, and connect families with specific resources. Care teams can do follow-up calls and screen for postpartum depression.

The need for culturally sensitive mental health care is especially critical when addressing the unique challenges faced by immigrant populations. Postpartum depression is not only prevalent among immigrant women, but they are 1.5 to 2 times more likely to experience it compared to non-immigrant women Falah-Hassani et al. (2015). Multiple factors contribute to depressive symptoms, including shorter duration of residence in the host country, limited social support, difficulties in marital adjustment, and perceived financial hardship (Falah-Hassani et al.). This increased vulnerability underscores the importance of implementing culturally sensitive healthcare services and tailored interventions that address both psychological and socio-environmental stressors. Such approaches are essential to effectively support the mental health needs of immigrant mothers and to reduce disparities in postpartum care, both of which can significantly impact infant health, as well.

When integrated services are not available, it is critical that providers collaborate or coordinate to the fullest extent possible. Patients need care throughout all stages of pregnancy, and if they have little choice in where they can access care early on, they are left without options in later stages. More providers must accept patients in these later stages to ensure patients receive

adequate care. When providers absolutely cannot accept patients, referrals with warm handoffs between providers are vital for facilitating patient trust and accurate transfer of data, so that patients are not left without recourse. A system of flexible appointment schedules among providers, including evenings after 5 PM and/or Saturdays, increases patients' ability to make it to appointments who disproportionately face work, financial, and transportation barriers.

### FORMALIZE THE ROLE OF PROMOTORAS DE SALUD IN HEALTHCARE SERVICES AND IMPLEMENT PROFESSIONAL HEALTH RECRUITMENT PROGRAMS FOR SPANISH/ENGLISH BILINGUAL HISPANIC EMPLOYEES.

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As discussed, focus group participants and providers frequently pointed out the need for Spanish-speaking employees in healthcare settings and for education on the U.S. healthcare system. To ensure successful care coordination for Hispanic patients, a system of integrated care must be developed that includes a more central and robust role of a bilingual, bicultural maternity care coordinator, such as a Promotora. Each patient should be offered and assigned a Promotora who acts as the primary, consistent, and trusted advocate and who serves as a base, linking the patient across all team members and areas of assistance or support. Formalizing the Promotora role includes specialized recruitment and training programs and extensive coverage for their services through Medicaid. Equipping the Promotoras de Salud workforce with tools and data empowers them to address systemic health challenges in the Hispanic community and provide critical navigation support and health education.

In addition to the Promotora role, bilingual (Spanish/English) and bicultural employees and Hispanic representation are needed at all levels in the healthcare system. Encouraging Spanish-speaking bilingual Hispanic youth to pursue health education careers at an early age is a critical first step in this process. We must think of ways to attract new generations to this field by recognizing their language and cultural skills as strengths that can be put to work for the well-being of their communities.

### CREATE INNOVATIVE STRATEGIES TO COMMUNICATE ABOUT SERVICES THAT ARE AVAILABLE, BUILD SOCIAL SUPPORT, AND PROVIDE EDUCATION.

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Even when multiple kinds of services are available, patients may not be aware of them or comfortable accessing them. As noted previously, Promotoras are essential for connecting patients with services. Groups and classes held at provider locations that offer social support and education not only provide essential information but also reinforce provider recommendations and build trust. When offered at the appropriate language and literacy levels, at convenient times (evenings or weekends) and locations, and with the provision of childcare, food, or other necessities, these services address social drivers of health.

Pregnancy and parenting groups facilitated by Promotoras provide a means to build social support and gain access to prenatal education and pregnancy screenings. Social support groups can be established for men and women to connect with others who understand what they are going through. Parenting classes and prenatal care groups can be organized to help attendees learn from healthcare providers and other pregnant women about managing the

transition to parenthood, along with addressing their social, emotional, medical, and practical needs.

Rethinking the healthcare delivery system is necessary to improving patient outcomes, especially among diverse populations who disproportionately bear the burden of structural barriers. Cross-functional collaboration and comprehensive care is key. Professionals in different roles can contribute knowledge and skills to achieve the common goal of quality patient care and a successful pregnancy. By working together, this system eliminates inefficiencies and errors and reduces provider burnout, while addressing barriers to care that patients face and creating a sense of community that enables patients to navigate the system.

### PRIORITIZE FLEXIBILITY, KINDNESS, AND PATIENCE WITH STRATEGIES TO BETTER UNDERSTAND PATIENTS AND PROMOTE HEALTHY BEHAVIOR

Racial discrimination and poor treatment at healthcare facilities are among the many factors that characterize minority populations and demonstrate strong correlations with high infant mortality rates (Jang and Lee, 2022). Identifying, acknowledging, and addressing these disparities is necessary before implementing strategies to mitigate them. Based on our survey results, provider-patient relationships are key to quality service. The majority of comments left by survey respondents about their satisfaction with providers were about being treated well and positive patient experience. They also mentioned liking services close to home and flexible payment options. Furthermore, federally qualified health centers (FQHCs) and other community-based clinics, which often provide comprehensive care and support services, were most frequently (48%) selected as locations where survey respondents felt most comfortable going for care.

Racism experienced during visits or interactions with the healthcare system, including perceived discrimination and discrimination based on undocumented status, can act as a significant barrier to accessing care, sometimes directly influencing the denial of care (Fryer et al., 2021). This supports statements from community members in our focus groups who frequently discussed the impact of fear associated with their immigration status and judgment by providers.

In January 2025, the executive branch of the federal U.S. government began and has continued to take actions to remove birthright citizenship through executive order and to deport immigrants, including revoking the legal status of some, without due process. Although the courts have challenged these actions, it is a slow and uncertain process. There remains a direct threat to the Hispanic community, in which newborn babies may be in legal limbo, and undocumented parents, including newly postpartum women, face threats of their own deportation.

This heightened fear increases the risk of complications for current pregnant women, who are already limiting their clinic visits due to fear of deportation. During the COVID-19 pandemic, NIHHC saw a similar trend, when many Hispanics feared going to local pharmacies to get vaccinated because their contact information would be shared with federal agencies. In addition, some clinics have stopped taking patients without health insurance.

The more the healthcare system increases the barriers to accessing services and exhibits unfriendly treatment, the more patients begin skipping appointments and finding other networks of support. As evidenced by our focus group results, for example, they start relying more on their small social circle for medical recommendations, daycare, and transportation, and they use social media for guidance in making decisions for the well-being of their infant.

Community-based and legal organizations can educate community members about the legality of the decisions being made in the federal government. However, public health organizations and providers must encourage community members to continue going to their doctor appointments and to trust in the medical system and its mission. Pregnant women should not risk jeopardizing their health or that of their baby. We make the following recommendations for any circumstances in which discrimination, whether intentional or not, is present, but with greater urgency considering the current climate and conditions.

### CONSIDER ACCEPTING WALK-INS, OFFER FLEXIBILITY FOR NO-SHOWS, AND PROVIDE ONE-ON-ONE CHECK-IN CALLS FOR PATIENTS WHO MISS AN APPOINTMENT.

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Clinics and providers need to be aware of the limitations experienced by patients (e.g., transportation and childcare) and respond accordingly, avoiding stereotyping or judging patients. Front desk staff can evaluate the reason a patient arrives late to an appointment instead of receiving them with the news that the appointment needs to be rescheduled, and they must pay a late fee for not arriving on time. When such policies exist, a sign in the waiting area or a text message, often in English only, is not sufficient to ensure patients are aware of and understand the policies in the context of the barriers we have discussed. Taking a moment to explain the policies and the reasons behind them empowers patients to take responsibility, to the extent they can, for their appointments. The empathy of the front desk staff can make a substantial difference in ensuring the patient returns to the doctor's office. When healthcare practices strive to create a welcoming and nonjudgmental environment, women and families continue to return for appointments.

### EXPAND THE KINDS OF DOCUMENTS ACCEPTED AS VALID FOR BECOMING A PATIENT.

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Many patients have an expired passport or Matricula Consular (an official government document that many Latin American countries provide certifying a person's nationality and identity while living abroad). Accepting this as a form of identification will increase access to services, reduce a chilling effect, and foster a comfortable, safe environment.

### IMPLEMENT REGULAR CULTURAL SENSITIVITY OR COMPETENCY TRAINING, ENCOURAGED BY LEADERSHIP, FOR PROVIDERS AND STAFF TO CREATE A MORE CARING AND DESTIGMATIZED ENVIRONMENT.

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Building trust and understanding between providers and patients is key to closing the gap in patients accessing perinatal care. For providers, cultural sensitivity or competency training is an opportunity to learn how the healthcare system works in other countries. They will then be

equipped to respond accordingly to specific requests and concerns. Leadership from organizations should set the pace about the culture and climate in FQHCs. Leaders need to lead by example by hosting regular staff activities including regular cultural sensitivity training and other events and actions to promote flexibility, kindness, and patience and to ensure high quality care throughout all phases of medical care.

### USE MOTIVATIONAL INTERVIEWING AS A TECHNIQUE TO UNDERSTAND PATIENTS AND EMPOWER HEALTH BEHAVIOR CHANGE.

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Providers and staff should consider specific ways to connect with patients, build empathy, create understanding, and empower healthy behavior. Motivational Interviewing (MI) is an established method that can be particularly effective for immigrant populations and in the context of prenatal care. MI is a collaborative conversational approach used by healthcare providers to actively engage patients in their care. It integrates technical skills—such as open-ended questioning and empathetic listening—with a patient-centered perspective, promoting introspection and empowering individuals to address health-related challenges (Emery and Wimmer, 2023). While MI has traditionally been applied in the context of substance use disorders, it can also be adapted for other areas of healthcare, including prenatal care. Cataldi et al. (2022) developed an MI-based intervention aimed at improving maternal immunization rates by enhancing patient engagement and addressing vaccine hesitancy through empathetic, patient-centered communication. Participants responded positively to interactive training elements and adult learning strategies. The results of this intervention demonstrate that the use of MI can positively influence birth outcomes.

As discussed, a new patient should be connected with a Promotora who serves as a welcoming champion and who can walk the patient through the rules and expectations of the clinic. These conversations can include discussions on the late fee, which should not be seen as a penalty, but as a reminder of the importance of canceling an appointment because it will open the opportunity to see another patient. During this conversation, the champion can help answer the question, “What can I do to help parents ensure a healthy pregnancy and the well-being of all infants?” Using nonjudgmental language is crucial when discussing needs, myths, and expectations, to encourage open and truthful conversations. Using multiple open-ended questions and prompts to fully identify and understand the social drivers of health that patients are facing and adapting conversations accordingly are key to addressing the unique circumstances of the patient and encourage best practices. This collaborative and asset-based approach empowers patients to take control of their health and well-being rather than solely relying on professional interventions. It focuses on building upon the strengths and resources of individuals and communities to improve health and well-being. Instead of solely addressing needs and deficits, it recognizes and utilizes existing skills, knowledge, relationships, and resources to support people's goals.

### FIND WAYS TO AMELIORATE FINANCIAL CONCERNS

The high costs of healthcare and lack of insurance are overwhelmingly the greatest concerns expressed by focus group participants and survey respondents. These factors directly

determine access to prenatal and regular care during pregnancy, which 17% of survey respondents rated as the number one factor impacting a healthy pregnancy and baby. Hispanics are disproportionately uninsured (20% compared to 12.6% countywide) in Elkhart County, and purchasing insurance is cost prohibitive. Even when community members do have insurance, the premiums, copays, deductibles, out-of-pocket limits, and costs of non-covered services make multiple doctor visits and procedures inaccessible for those with low or unstable income. When they can no longer afford doctor visits or they have pending bills to pay, as many focus group participants stated, they stop going to them. Survey respondents (16%) rated access to health insurance/Medicaid as the greatest need. Our study suggests that finding ways to ameliorate financial concerns, specifically by increasing access to insurance and prenatal care, is the top priority in addressing infant mortality in the Hispanic community. Data from the Indiana Department of Health shows that perinatal risks is the top cause of infant mortality, both overall (3.2) and among Hispanics (3.6) (2023a). Early and regular prenatal care is crucial for identifying and managing these risks, ultimately improving pregnancy outcomes.

Addressing the complexity of provider availability, provider shortages, and relationships between healthcare providers, hospital systems, and insurance companies cannot be ignored when considering how to address financial concerns at both the systemic level and level of face-to-face interaction with patients. Recent developments in Elkhart County expose the instability of provider access. Although Elkhart County is not considered a maternity care desert (reference), patients do not always have access to providers. Federally Qualified Health Centers (FQHCs), whose mission is to provide comprehensive, high-quality, and affordable primary and preventive care services to underserved populations, regardless of their ability to pay or insurance status, depend on local hospitals for extended services such as delivery. Yet, many physicians at Elkhart County's local hospitals have recently resigned or retired. This unfortunate circumstance affects FQHCs directly. In addition, a prenatal care center in the neighboring St. Joseph County, which covers a larger metropolitan area, was closed. This increased the flow of patients to the Elkhart County area providers, making the situation worse. With few providers, especially in obstetrics and gynecology, at the hospitals, providers were overwhelmed with more patients and fewer staff, and FQHCs were affected by default. Hospitals could not take many patients and had to reduce prenatal care services. A major consequence was a limit in the number of deliveries per month that hospitals would accept from FQHCs. The number of patients hospitals could receive was subject to the delivery due date of each patient, otherwise patients must be referred directly to the hospital. While this phenomenon is not unique to Elkhart County, it highlights the disproportionately negative impact of provider shortages on low-income and uninsured patients, who then face higher fees and additional hurdles to receiving care in hospitals. The following recommendations consider immediate ways to ameliorate financial costs at clinics and policy-level actions to increase access to perinatal care.

### CONSIDER PROVIDING SELECT FREE SERVICES AND RESOURCES, DISCOUNTS, AND CLEAR EXPLANATION OF COSTS.

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Providing free services such as ultrasounds in the first trimester and mental health counseling are feasible adjustments, especially when coordinated with providers in an integrated health system, that can have an immense impact on patients with financial concerns. Collaborating

with social service providers and companies can also ensure free vitamins, diapers, wipes, formula, car seats, and sleeping boxes (i.e. cribs are often not used due to space issues within housing, thus safe sleep boxes may be a better solution). Discount letters from provider offices should be offered to patients who can present them to hospitals for discounted bills, and coupon books can be offered. Regardless of whether free services are offered, patients should be provided with the clear cost of services and possible bills they will receive (e.g., doctor visits, radiology, labs, etc.) in writing. Providers can list the discount(s) available and patients' eligibility for them. It is critical to connect patients with financial help at hospitals, so they can negotiate payments or pay up front with reasonable discounts.

### ADVOCATE FOR EXPANDED ACCESS TO MEDICAID COVERAGE FOR PRENATAL AND POSTNATAL CARE.

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Many states do offer expanded access, which Indiana could consider, and which would significantly reduce healthcare costs long-term. Expanded Medicaid eligibility among low-income women of reproductive age has been associated with increased healthcare coverage and utilization, better self-rated health, and decreases in avoidance of care because of cost and alcohol use, suggesting that it could ultimately improve preconception health (Margerison et al., 2019). In 2021, 24% of Hispanics never received prenatal care (Indiana Department of Health, 2023a), and the current maternal vulnerability index in Elkhart County is high at 70.4 (March of Dimes, 2024a). NIHHC has proposed a prenatal care voucher pilot program in which pregnant women enrolled in Emergency Medicaid in Elkhart County would be eligible for a voucher to receive prenatal care medical services and maternity care coordinator (MCC) time that provides support, follow-up between medical appointments, and liaising between the patient and providers for healthcare and social services. This program specifically aims to increase access to prenatal care for low-income and under-resourced pregnant women who are not eligible for any other kind of health insurance assistance. The uniqueness of this proposal is the partnership between the provider that will care for eligible pregnant women during pregnancy (prenatal care) until delivery and the MCC, who will play a vital role in facilitating that continuum of care, acting as the bridge between the pregnant women and the health facility. This scenario is critical to reducing infant mortality in Elkhart County. Barriers addressed include financial barriers and lack of insurance; educational, language, and cultural barriers; and in general, the social drivers of health that serve as barriers and prevent patients from attending appointments or reduce their chances for successful outcomes.

### EXPAND MATERNITY LEAVE.

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Focus group participants discussed the impact of the lack of maternity leave in their workplaces and the fear of losing their jobs. It was especially confusing to them when compared to the more generous maternity leave offered in many Latin American countries. Expanding maternity leave would enhance community members' access to perinatal, ameliorate financial costs, and reduce infant mortality. The implementation of paid family leave policies has been proven to be an aid in the reduction of infant mortality rates in the U.S., especially when focusing specifically on

outcomes such as birth weight, preterm birth rates, and infant mortality within the first year of life (Montoya-Williams et al., 2020) For example, California enacted the first partial pay family leave policy in the nation, and post neonatal mortality rates dropped by 12% (Montoya-Williams et al.).

### LIMITATIONS

#### QUALITATIVE

A limitation of the qualitative study is that participants reflected on their experiences retrospectively. It is possible that information shared may have been affected by recall bias. Additionally, trustworthiness of the data could have been enhanced with member checks, where the results of the study are returned to the participants to see if results accurately reflect their experiences. The study size was small, as is the nature of qualitative studies, however the sample size did not allow for more in-depth interpretations, such as the influences of participants' country of origin on their experiences. Future studies should include larger and more diverse samples.

#### QUANTITATIVE

The findings of the quantitative study should be interpreted with several limitations in mind. First the cross-sectional survey design limits the robustness of the results due to its static nature. A cross-sectional study, also known as a descriptive study, collects data from a population at a single point in time. It's like taking a snapshot of a group of people, measuring both their exposures and outcomes simultaneously. While useful for describing characteristics of a population, identifying prevalence of health outcomes, and examining relationships between variables, our cross-sectional design did not enable us to show cause-and-effect relationships, or analyze behavior over time. Secondly, the quantitative surveys did not collect data about the pregnancy status of these survey respondents. Without data on pregnancy status, it's difficult to gain a specific understanding of how pregnancy influences the phenomenon being studied and the surveyed sample may not accurately reflect the diversity of experiences related to pregnancy. Thirdly, the unique characteristics of the study setting and sample further constrain the generalizability of the results.

### CONCLUSION

The overall aims of this project were to develop a conceptual model of perinatal health, explore community perceptions of infant mortality, and assess related services for the peripartum, prenatal, and postpartum periods for Hispanics in northern Indiana. We explored the community's awareness, knowledge and attitudes towards perinatal health, the barriers they face in accessing services, and the needs and gaps they identify in their pursuits towards health and wellbeing.

Our results suggest that there are low levels of awareness and knowledge regarding infant mortality, with many individuals unfamiliar with the term ‘infant mortality,’ the majority not correctly identifying it as a problem in their community, and a significant portion is also unfamiliar with the causes of infant mortality. While there are low levels of knowledge and awareness on infant mortality, individuals desire to know more, thus it is important for health communication campaigns to address this gap. Similarly, it is important to provide additional information on perinatal health services available in the northern Indiana community, such as Emergency Medicaid and WIC. However, it is also important to actively work to expand Emergency Medicaid since the lack of health insurance is a salient concern among community members. Other concerns include financial instability, lack of affordable housing, and difficulty accessing healthcare services. Our results indicate that individuals understand the importance of prenatal care and appropriate health behaviors but are challenged by social and financial factors such as stressful and inflexible work environments, fear of discrimination, and childcare and transportation concerns. They articulated the need for easier access to the healthcare system, as well as a need for sexual health education and information on safe sleep. Because of language and cultural barriers and low health literacy, particularly in the context of the U.S. healthcare system, it is important to use trusted messengers, such as Promotoras de salud, to facilitate access to services and resources.

Based on qualitative and quantitative data, we have identified barriers to perinatal health and well-being across various levels of the socio-ecological model and provided a list of recommendations that could be used to bridge the gaps and needs identified. These recommendations range from prioritizing home visits, to emphasizing kindness and patience in check-in procedures at healthcare clinics, to utilizing motivational interviewing in patient-provider encounters, to providing financial assistance and discounted bills, to advocating for paid maternity leave policies. In moving forward, using communication channels identified by community members to provide health education is important. Those include social media such as Facebook, WhatsApp, and in-person events.

Based on the barriers that exist on individual, interpersonal, organizational, and community and policy levels, it is critical to work collaboratively, rather than in silos, given the complex interplay of factors.

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## APPENDICES

### APPENDIX A: INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS

#### Introduction

Thank you for your time today! We will be discussing your thoughts, opinions, and perceptions about infant mortality, *or the deaths of infants before the age of 1*, in our community.

- Remind participants that everything they say is confidential. We will not share their name.
- We will collate their anonymous responses with others to share patterns and general themes in the data.
- Ask for consent to audio-record the interview and explain that the recording will be professionally transcribed (without their name).

#### Questions

1. To start off, we want to get a feel for how much of a problem you believe infant mortality is in our community. Would you rank it as a high priority problem, mid-priority problem, or low priority problem?
  - a. Why did you rank it that way?
  - b. Is it a problem in some zip codes compared to others? What zip codes? Why is it more of a problem there?
2. Is infant mortality a problem among the Latino/Hispanic population in our community? Why?
  - a. What subpopulations are most at-risk in your opinion? (immigrants vs. non-immigrants, regional populations, age, partnered vs. non-partnered, etc.)
3. Can you describe to me what you see as the major causes of infant mortality are among the Latino/Hispanic population in our community?
4. In your opinion, what are some issues or problems closely associated with infant mortality among the Latino/Hispanic population in our community?
5. Are there services in our community that can address [list the causes or problems that have been mentioned]?
  - a. Are those services used? Why or why not? If not used, what are the barriers?
  - b. Among whom are the services used?
  - c. How are these services perceived among the Latino/Hispanic community?
  - d. How do services need to be adapted or changed?
6. Can you talk about the services YOUR organization provides [that address the causes or problems mentioned earlier]?
  - a. How have you adapted your services for the Hispanic/Latino community?

- b. In what ways might your services still need to be adapted for the Hispanic/Latino community?
7. What services still need to be created to reduce infant mortality among the Hispanic/Latino community?
  - a. What are the challenges in creating those services?
8. Based on your best understanding, what are the barriers that the Hispanic/Latino community face for:
  - a. Sex education
  - b. Pre-conception health
  - c. Prenatal care
  - d. Postpartum mental health
  - e. Well-child visits
9. If you could wave a wand and “change” something for moms, dads, families, and babies in our community, what would that be?
10. Based on your best understanding, what are the attitudes that may hinder appropriate prenatal/postpartum or infant care?
  - a. Attitudes among Moms? Dads? Teenagers? Grandparents? Providers? Others?
11. Based on your best understanding, what are the behaviors that may hinder appropriate prenatal/postpartum or infant care?
  - a. Behaviors among Moms? Dads? Teenagers? Grandparents? Providers? Others?
12. Based on your best understanding, what is lacking in knowledge that hinders appropriate prenatal/postpartum or infant care?
  - a. Knowledge among Moms? Dads? Teenagers? Grandparents? Providers? Others?
13. Based on your best understanding, what structures hinder appropriate prenatal/postpartum or infant care?

Thank you so much for your time!

**New Questions:**

1. Financial concerns consistently rise to the top as a contributing factor to delayed or absent prenatal or postpartum care, lack of lab work, or specialty care. Is there a way to overcome that barrier? If so, what are your ideas?
2. What are your ideas for increasing trust among undocumented clients and the medical system?

3. Social drivers of health, such as housing, play a role in infant mortality. How do the challenges associated with housing affect infant mortality, in your opinion?
  - a. What are the best ways to address co-sleeping or other safe sleep challenges, in your opinion?
4. What is the role of an OB shortage in Indiana? Is this an exaggerated or realistic concern? How does it affect Latino patients?
5. What are your experiences with helping Latino patients navigate the US healthcare system? What are the biggest challenges? What successes have you had?
6. In terms of health education knowledge, what do Latino patients most need to know in order to have a healthy pregnancy? What do you sense that they do not understand, do not know, or do not practice?
7. What are some of the best ways to address mental health concerns of new parents?
8. Latinos/Hispanics are not a monolithic group, of course. From your perspective, what subgroups are in need of particular help when it comes to healthy pregnancies? Newly arrived immigrants? Venezuelans? Mexicans? Etc. What are some of their unique needs?

APPENDIX B: FOCUS GROUP GUIDE FOR HISPANIC COMMUNITY MEMBERS

**Introduction**

Thank you for your time today! **We will be discussing your thoughts, opinions, and perceptions about infant mortality, or the deaths of infants before the age of 1, in our community.**

- Remind participants that everything they say is confidential. We will not share their name.
  - We will collate their anonymous responses with others to share patterns and general themes in the data.
  - Ask for consent to audio-record the interview and explain that the recording will be professionally transcribed (without their name).
1. What do you think about when we say the word “infant mortality”?
  2. To start off, we want to get a feel for how much of a problem you believe infant mortality is in our community. Would you rank it as a high priority problem, mid-priority problem, or low priority problem?
    - a. Why did you rank it that way?
  3. Infant mortality (or the number of babies who die before the age of one) is very high in the Latino community, particularly this zip code: [xxxxxx]. Why do you think that is?
  4. Can you describe to me what you see as the major causes of infant mortality are among the Latino/Hispanic population in our community?
  5. What are things you feel like contribute to having a healthy pregnancy or healthy baby?
    - a. **\*\*Let participants list ideas\*\*** **\*\***
      - i. Do you think age at pregnancy matters to having a healthy pregnancy or baby? Why or why not?
      - ii. What role does nutrition play in having a healthy pregnancy or healthy baby?
      - iii. Does being overweight affect a pregnancy? Why or why not?
      - iv. Do you think prenatal care is important? Why or why not? When should women go to prenatal care?
      - v. What affect does tobacco / smoking have on a pregnancy or a baby?
      - vi. Do you know when a full-term birth is? Why is a full-term birth important? What happens if the baby is not full-term? (Full-term births (i.e. when a woman delivers at or after 39 weeks of pregnancy) / preterm births (i.e. when a woman delivers before 37 weeks of pregnancy))
      - vii. What role does relationship stress have on a healthy pregnancy or healthy baby? Why does it matter?
      - viii. Does mood or depression play a role in healthy pregnancies or healthy babies? Why or why not?

- ix. Is it okay to sleep in the same bed as a baby? Why or why not? Should you use bumper pads and other things in cribs? Why or why not? Is it okay for babies going to sleep with a pacifier? Why or why not? Can babies go to sleep on their back? Why or why not?
    - x. Do you think breastfeeding should be prioritized? Why or why not?
    - xi. Do you have ideas for how to prevent accidents that could harm your baby? What ideas do you have?
6. What are some challenges or difficulties you think you might experience in taking care of your baby or keeping him/her healthy and safe?
  - a. What kind of challenges have you experienced in the past when you had a new baby?
  - b. Do other people in your community have trouble taking care of their babies? In what ways?
  - c. What about other people in your family?
7. What are some strengths you think the Latino population has in taking care of babies?
8. What are some resources (e.g. in community, family, friends) that will help you be a good mom, dad, or caretaker? What are some of those resources?
  - a. Do you use those resources? If not used, what are the barriers?
  - b. Do any of those services need to be adapted or changed to better serve you?
9. In your opinion, does the Latino community have enough information on sex education? Why or why not?
  - a. In your opinion, does the Latino community have enough information on pre-conception health? Why or why not?
  - b. In your opinion, does the Latino community have enough information on prenatal care? Why or why not?
  - c. In your opinion, does the Latino community have enough information on postpartum mental health? Why or why not?
  - d. In your opinion, does the Latino community have enough information on well-child visits? Why or why not?
10. If you could wave a wand and “change” something for moms, dads, families, and babies in our community, what would that be?
11. What can community agencies (hospitals, clinics, birthing centers, doulas, midwives, schools, employers) do to prevent infant mortality?
  - a. What can they do?
  - b. What about other agencies or organizations?
12. Do you think infant mortality is preventable? Why or why not?
  - a. Do you think other people think it is preventable? Why or why not?

13. What are some questions that moms, dads, or caregivers might have about taking care of their child during pregnancy or after that they might not feel comfortable asking?
14. Is there anything else that you think is important for other parents or other caregivers to consider about preventing infant mortality?

APPENDIX C: FOCUS GROUP DEMOGRAPHIC SURVEY

**DEMOGRAPHIC SURVEY – NIHC**

1. Gender/Sex (circle one):    Male    Female
  
2. Age: \_\_\_\_\_
  
3. Relationship Status (circle one): Single    Married    Boyfriend/Girlfriend    Divorced    Separated
  
4. Country of origin: \_\_\_\_\_
  
5. What is the highest level of education you have completed? *(Mark the highest level you completed)*  
 Elementary:     1st             2nd             3rd             4th     5th     6th  
 Middle School:     7th             8th  
 High School:     9th             10th             11th             High School degree/GED  
 College:     some             College degree     Technical Degree     Other – Which? \_\_\_\_\_
  
6. What type of health insurance do you have? *(Mark all that apply)*  
 Health insurance through my job     I buy my own health insurance     Medicaid     Emergency Medicaid     HIP  
 I do not have health insurance     I am on my parent's health insurance     Other \_\_\_\_\_
  
7. What language is spoken the most in your home? *(Mark just one)*  
 Spanish only             English only             Both English and Spanish equally well  
 More English than Spanish     More Spanish than English     Other – Which language? \_\_\_\_\_
  
8. If English is not your first language, how well do you speak English? *(Mark just one)*  
 Very well             Well             Not very well             I do not speak English
  
9. Last week, which of the following was your main activity? *(Mark all that apply)*  
 Employed             Homemaker     Retired             Babysitter             Unemployed (looking for a job)    Student
  
10. If you are retired, do you receive social security benefits? If not retired, please skip.  
 Yes     No
  
11. If you were employed during the last week, which of the following describes your job? *(Mark all that apply)*  
 Worked less than 20 hours     Between 20 & 32 hours     Between 32 & 40 hours     More than 40 hours  
 I had 1 job             I had 2 jobs             More than 2 jobs    I work mostly during the day  
 I work mostly during the night
  
12. Who do you go to when a member of your family needs to see a doctor? *(Mark all that apply)*  
 I have a primary care doctor             I go to urgent care clinics             I use the emergency room or hospital  
 I don't know who to go to            I go see a friend or family member            I go to health fairs
  
13. From the following choices, which are the main barriers you face in accessing healthcare in this area?  
*(Mark all that apply)*  
 Language             I do not understand the health system rules             Racism/Discrimination  
 It's expensive             They do not receive patients without insurance             Hours of operation  
 Transportation             None             Other Which one? \_\_\_\_\_
  
14. Do you drive a vehicle regularly?  
 Yes     No
  
15. Do you have any of the following? *(Mark all that apply)*  
 Obesity     High cholesterol     Diabetes     High blood pressure     Depression     Tobacco use/smoking

## From Infant Mortality to Infant Vitality

Relationship stress    Other

16. What statement best describes your current living condition? *(Mark all that apply)*

I live alone    I live with family members    I live with others who are not related to me

17. Do you feel socially isolated?  Yes    No

18. If you were not born in the U.S., in what year did you move to this country? \_\_\_\_\_

19.

	Yes	No	Not applicable	
Have you been pregnant (women) or has your current partner (men) been pregnant?	How many times?  How many babies were born?			
Are you currently or recently pregnant?	Check one: <input type="checkbox"/> 1 <sup>st</sup> Trimester <input type="checkbox"/> 2 <sup>nd</sup> Trimester <input type="checkbox"/> 3 <sup>rd</sup> Trimester <input type="checkbox"/> Postpartum			When is your baby due?
Do you have a child/children?	How many?			Ages of child/children:
Has one of your children ever died, from birth to 12 months of age?	At what age?			
My child/children spend time each week with a caretaker/babysitter.	How many hours?			
A child of mine was born below 5 lbs 8 oz.				
A child of mine was born pre-term (before 37 weeks).				
I saw my doctor regularly for prenatal care (check-ups) during my pregnancy.	What week did you start?			
I breastfed at least one of my children.	When did you stop?			
I first became a parent when I was a teenager.	What age?			

APPENDIX D: DEMOGRAPHIC SURVEY

**Demographic Survey = Encuesta Demográfica**

Thank you for attending our health fair! Please help us by filling out this demographic survey.

¡Gracias por asistir a nuestra feria de salud! Por favor ayúdenos a completar esta encuesta demográfica.

**Gender = Género:** \_\_\_\_\_

**Age = Edad:**

- Under 18 = menor de 18       45-54
- 18-24       55-64
- 25-34       65 or over = mayor de 65
- 35-44

**Race = Raza:**

- White/Caucasian = Blanco
- Black/African American = Afroamericano
- Asian = Asiático
- Native American/American Indian = Nativo Americano
- Multiracial = Multi-racial
- Other (please specify) = Otro (especifique por favor)

**Ethnicity = Etnia:**

- Hispanic/Latino = Hispano/Latino
- Not Hispanic/Latino = No Hispano/Latino

**Country of Birth = País de Nacimiento:**

**Highest Education Level = Nivel de Educación más Alto:**

- Elementary = Primaria      Grade = Grado: \_\_\_\_\_
- Some high school = Algunos años de Prepa / Bachillerato
- High school graduate/GED = Graduado de Prepa /GED
- Some college or associate degree = Algún nivel de estudios universitarios
- Bachelor's degree = Licenciatura
- Master's degree = Maestría
- Doctorate = Doctorado

**Place of Work = Lugar de Trabajo:** \_\_\_\_\_

- Other (please specify) = Otro (especifique por favor) -

**Geographic Location = Ubicación Geográfica:**

Zip code or County = Código Postal o Condado: \_\_\_\_\_

**Language Preference = Idioma preferido:**

What is your preferred language for communication? =

¿Cuál es su idioma de comunicación preferido?

- English = Inglés
- Spanish = Español
- Both = Ambos
- Other (please specify) = Otro (especifique por favor) -

APPENDIX E: INFANT MORTALITY SURVEY

**SURVEY ON INFANT MORTALITY – NIHHC**

1. What does the term “infant mortality” mean to you? *(Mark only one)*  
 A miscarriage (the death of a fetus before the 20<sup>th</sup> week of pregnancy)    An abortion (termination of pregnancy)  
 The death of a baby at birth     The death of a baby or child (younger than 18)     The death of an infant before the age of 1  
 I don't know
  
2. What do you think are the major causes of infant mortality in Elkhart County? *(Mark all that apply)*  
 Birth defects     Premature birth/low birth weight     Health complications of the mother during pregnancy  
 Unsafe sleep practices (SIDs/SUIDs)     Assaults/injuries     I don't know     Other \_\_\_\_\_
  
3. For a healthy pregnancy and baby, we need to think about \_\_\_\_\_. *(Mark all that apply)*  
 Nutrition     Prenatal care/regular checkups during pregnancy     Age of mother at pregnancy (not too young or too old)  
 Not drinking     Not smoking     Mother's mental health     Mother's weight     Breastfeeding     Sleep habits  
 Controlling mother's health conditions (diabetes, hypertension, obesity)
  
4. When I think about taking care of a baby and/or keeping them safe, in this country and especially in Indiana, my main concerns are \_\_\_\_\_. *(Mark all that apply)*  
 Not enough food     Can't afford clothing/baby supplies     Unsafe/inadequate housing     Don't speak English  
 Don't have health insurance/Medicaid     Don't understand the health system     No transportation     Inflexible work hours  
 Can't afford doctor visits     I am new in this country     Don't have a doctor     Little or no support from family/friends
  
5. If someone told you that the highest “infant mortality” rate among Hispanics in Indiana is in Elkhart County, would you believe it?  
 Yes     No
  
6. Why or why not? \_\_\_\_\_
  
7. For a successful pregnancy and healthy baby, my life would be easier with \_\_\_\_\_. *(Mark all that apply)*  
 Financial stability     Safe/stable housing     Strong family/friends support     Health Insurance/ Medicaid     A job  
 Better understanding of the health system     Transportation     Manageable work hours     Migrant status resolved  
 Fluent in English     Access to health care services     Access to educational programs
  
8. I think in this area (Elkhart Co.), we need more places that offer information/services on the following topics: *(Mark all that apply)*  
 Sex education     Preconception health     Prenatal care     Postpartum mental health     Well-child visits  
 Other \_\_\_\_\_
  
9. What communication channels do you think would be more appealing to the Hispanic community to promote preventative health campaigns (such as Infant Mortality)? *(Mark all that apply)*  
 Facebook     WhatsApp     Bus advertisements     Billboards     Radio     TV     Brochures/Pamphlets  
 Videos     NIHHC website     In person educational event     Online webinar     Podcast     Pandora
  
10. Do you know what Emergency Medicaid is?     Yes     No
11. Do you know what the WIC Office is?     Yes     No
  
12. How satisfied are you with the health care services you have received in the Elkhart County area?  
*(3 = very satisfied, 1 = not satisfied at all)*  
 3     2     1
  
13. Where have you gone for medical services? \_\_\_\_\_
  
14. If you or your partner were expecting a baby, where would you feel comfortable receiving prenatal care services? *(Mark all that apply)*  
 Maple City Health Care Center     Heart City Health Center     RETA     Women's Care Center  
 Goshen Physicians OB/GYN     Goshen Physicians Family Medicine with OB Pro Park  
 Beacon Medical Group Obstetrics & Gynecology Elkhart
  
15. Why would you choose this provider? \_\_\_\_\_

APPENDIX F: LINE-BY-LINE CODES

Nodes			
Name	Sources	References	
A safe and non judgemental atmosphere helps patients keep coming back	2	2	
Access to healthy food is an issue that affects IM	1	1	
Action taken to combat high IM rate	1	2	
Accepting all types of patients	1	1	
Doulas for extra support and translation during delivery	1	1	
Education about safe sleep	1	1	
Extending classes and resources until child reaches the age of 5	1	1	
Flexibility for no shows, providing care even if they don't show for the first or second appointment	1	1	
Free access to early prenatal care	2	3	
Free mental health counseling	1	2	
Free ultrasounds in the first trimester	1	1	
Having navigators on staff to help people sign up for medicaid and other health insurance	1	2	
Having social workers as part of the resource team to support with various topics	3	4	
Helping patients get on Medicaid or Package or Emergency medicaid E to help cover costs along pregn	3	4	
helping with financial assistance applications	2	2	
Helping women make an informed choice in terms of keeping a pregnancy and unwanted pregnancies	1	1	
Nutrition education as part of early prenatal preventative care	2	2	
One on one calls if patient cannot make it to the prenatal groupo class	1	1	
Overcoming language and cultural barriers	1	2	
Parenting classes with insentives that clients can use to buy necessities for their babies	1	1	
Patient education documents and paperwork in Spanish	1	1	
Post partum care as a way to address IM	2	2	
Post partum mental heahl is being provided	2	2	
Provide assessments in a motivational way, where the patient more openly shares their needs and expe	1	1	
Providing care even if people cannot pay for it	1	1	
Providing free pre-natal vitamins, diapers, whipes, formula, car seats, cribs, sleeping equipment	1	2	
Providing interpreters	1	1	
Providing support for younger pregnant girls to tell their parents, coworkers, school	1	1	
Providing transportation to office visits	1	1	
Spanish speaking providers	3	7	
Walk-ins to reduce the waiting time for early prenatal care	1	1	
Causes of high rates of IM in Hispanic comunity	0	0	
Financial instability due to employment that is not secure or under a false name	1	1	
Food insecurity	1	2	
housing insecurity	2	5	

## From Infant Mortality to Infant Vitality

Name	Sources	References
housing insecurity	2	5
Lab work is expensive for providers and pregnant women	2	2
Lack of access to Healthy Babies and WIC due to undocumented status	1	1
Lack of funding and personnel for serving institutions affects the amount and level of services	1	2
lack of medical care	1	3
lack of proper equipment related to safe sleeping practices	1	3
Lack of sex education	1	1
No early prenatal care	1	2
Fear due to stigma	2	2
Not seeking prenatal care	1	3
Discrimination	1	2
lack of a primary care provider	2	3
Lack of childcare for women to go to appointments	2	2
Lack of education	1	3
lack of insurance	3	8
Lack of Spanish speaking providers	3	6
Lack of time to seek care	1	3
Lack of transportation	4	9
Lack of trust in providers	3	4
Lack of understanding about the health system in the United States	3	10
Patients do not know the full scope of service of the service organization	1	1
People are scared to seek care due to undocumented status	1	2
People think early prenatal care is unnecessary	2	2
Prenatal care is expensive	4	10
Sub population of Latinos more at risk of not seeking early prenatal care	3	5
There may be cultural, religious or traditional influences on family planning, birth control on con	1	1
The structure of the health system is not welcoming to new pregnant women in need	1	2
Once assistance documentation is filed, it may take 30 to 60 days for a response	1	1
Social determinant of health play a big role in high rates of IM in Hispanic community and zip code 465	1	1
Causes of high IM specific to 46516	1	2
Collaboration with local hospitals for discount letters	1	2
Communication between medical providers and factories is needed for consideration for pregnant women d	1	1
Cultural beliefs, traditions and practices that affect IM	0	0

## From Infant Mortality to Infant Vitality

<ul style="list-style-type: none"> <li>Cultural beliefs, traditions and practices that affect IM</li> </ul>	0	0
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Contraceptives in Mexico and other countries can be bought over the counter.</li> </ul> </li> </ul>	1	1
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Cultural belief that covering the baby is always necessary can lead to overheated babies and SIDS</li> </ul> </li> </ul>	1	1
<ul style="list-style-type: none"> <li>Education about nutrition and physical activity takes place in early prenatal care and lack of this poses a hi</li> </ul>	1	2
<ul style="list-style-type: none"> <li>Education about safe sleep is helpful in lowering IM numbers</li> </ul>	2	2
<ul style="list-style-type: none"> <li>Education is fundamental to prevent infant mortality</li> </ul>	4	12
<ul style="list-style-type: none"> <li>Having a supportive partner plays a big role in post partum mental health</li> </ul>	2	2
<ul style="list-style-type: none"> <li>High rate of substance abuse associated with IM, not necessarily in the Hispanic population</li> </ul>	1	3
<ul style="list-style-type: none"> <li>High rates of infant mortality in the hispanic community</li> </ul>	2	4
<ul style="list-style-type: none"> <li>Home visits are no longer provided because even though they were successful, there is no funding for them</li> </ul>	1	2
<ul style="list-style-type: none"> <li>ideas for combating the problem of IM</li> </ul>	2	2
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Expanding the coverage of Emergency Medicaid to cover prenatal care</li> </ul> </li> </ul>	1	1
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Lobbying for a change in the laws at the government level</li> </ul> </li> </ul>	2	2
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Midwifery is a good option for Hispanic moms due to the lower cost of care</li> </ul> </li> </ul>	1	1
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Providers do not think anything new needs to be done, just emphasize and more resources for what is</li> </ul> </li> </ul>	1	2
<ul style="list-style-type: none"> <li>IM is a big problem in our community</li> </ul>	4	10
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>IM is a high priority issue when comparing local rates to the rest of the state, country and the world</li> </ul> </li> </ul>	1	1
<ul style="list-style-type: none"> <li>Immigrants from Mexico and Central American countries lack the support of extended family in the post p</li> </ul>	1	2
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>The Cuarentena is not observed here because of lack of support, doctor's orders or the need to go out t</li> </ul> </li> </ul>	1	2
<ul style="list-style-type: none"> <li>Importance of a holistic approach to care</li> </ul>	2	2
<ul style="list-style-type: none"> <li>Information on statistics has been presented by administrators as well as Health department, but provider</li> </ul>	1	1
<ul style="list-style-type: none"> <li>It is difficult for women to get specialty care, labs or imaging outside of the scope of their primary care clin</li> </ul>	1	2
<ul style="list-style-type: none"> <li>It is important to create support communities around recently arrived immigrants</li> </ul>	1	1
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Newly arrived immigrant families are at a higher risk of IM due to housing insecurity and lower educatio</li> </ul> </li> </ul>	1	1
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Newly arrived immigrants may not have access to consistent birth control and seem to get pregnant so</li> </ul> </li> </ul>	1	2
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Newly arrived immigrants need more in-depth explanations about services</li> </ul> </li> </ul>	1	2
<ul style="list-style-type: none"> <li>Legislation in the state of Indiana influences the terrible IM statistics</li> </ul>	2	2
<ul style="list-style-type: none"> <li>Limited access to midwives in the area</li> </ul>	1	1
<ul style="list-style-type: none"> <li>Low percentage of Hispanic teen pregnancies</li> </ul>	1	1
<ul style="list-style-type: none"> <li>Many people only have emergency Medicaid, which only covers the delivery, so there would be a charge fo</li> </ul>	2	4
<ul style="list-style-type: none"> <li>Many providers do not accept patients with Medicaid</li> </ul>	1	1
<ul style="list-style-type: none"> <li>Migration process does not allow for a safe place to get prenatal care</li> </ul>	1	2
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Migration process creates a gap in medical care in general, maybe affecting pregnancy rate</li> </ul> </li> </ul>	1	1

## From Infant Mortality to Infant Vitality

<input type="radio"/>	There is a shortage of mental health providers in the Elkhart area		1	2
<input type="radio"/>	There is an abundance of zip code specific resources for Hispanics in South Bend, but many barriers associ		1	2
<input type="checkbox"/>	There is an inconsistency in the provider that sees patients through prenatal care and the team that actual		2	5
<input type="radio"/>	Late in their pregnancy, patients move on to other providers that will deliver the baby		1	1
<input type="radio"/>	Prenatal care at the final stages of pregnancy is crucial to address mortality, women seem to no have g		1	1
<input type="radio"/>	Referrals are made at 34 weeks to different providers and hospitals that will attend the delivery, with diff		0	0
<input type="radio"/>	Women are not admitted into prenatal care OR a delivering physician if they want to initiate care late in		1	1
<input type="radio"/>	Women seeking early prenatal care find that providers are booked for weeks, and many times they are		1	2
<input type="radio"/>	Women transfer out of program after 20 weeks gestation, to a provider of their choice		1	1
<input type="radio"/>	There is and overall confusion about the Medicaid packages and the services they cover and do not cover.		2	3
<input type="radio"/>	There is difficult access to the newer vaccines that prevent SRV due to shortage		1	1
<input type="radio"/>	There seems to be a need for a medical home for prenatal care, where they can be seen and provided for t		1	1
<input type="radio"/>	Undetected or untreated chronic disease during pregnancy poses a higher risk for IM		1	2
<input type="radio"/>	Unsafe sleep is perceived as a primary cause of infant mortality, and one that should be diligently targeted		1	1
<input type="radio"/>	Well visits for infants are difficult due to lack of childcare and transportation		1	1
<input type="radio"/>	Word-of mouth is a powerful referral tool among Hispanic women seeking prenatal care		1	1
<input type="radio"/>	Wrong use of carseats or second hand carseats, not specific to Hispanics but valid		1	1
<input type="radio"/>	Younger immigrants want to adapt to the ways of the US and not pay so much attention to the way things		1	2

## From Infant Mortality to Infant Vitality

<input type="radio"/>	More communication of health records is needed between countries and states for migrating pregnant wo	1	1
<input type="radio"/>	Mothers are incentivated towards breastfeeding due to the low costs, but many face having to work soon a	1	1
<input type="radio"/>	Need for post partum mental health education	2	2
<input checked="" type="checkbox"/>	<input type="radio"/> Partners tend to accompany women to their prenatal visits, talking about Hispanics	1	1
<input type="radio"/>	<input type="radio"/> Percentage of Hispanic patients in Prenatal setting that speak Spanish	1	2
<input type="radio"/>	<input type="radio"/> Poor access to contraception after delivery causes women to get pregnant soon after, thus elevating the ris	1	1
<input type="radio"/>	<input type="radio"/> Provider thinks that fathers and extended family would not be willing to come to education sessions	1	1
<input type="radio"/>	<input type="radio"/> Providers assume that Hispanics know certain things due to traditions, but in fact the need the same amou	1	1
<input type="radio"/>	<input type="radio"/> Providers do not think there is a shortage of organizations and doctors who can provide prenatal care	2	2
<input type="radio"/>	<input type="radio"/> Providers estimate that around 10 or 15 percent of their pregnant patients are migrators, or migrating duri	1	1
<input type="radio"/>	<input type="radio"/> Providers feel there is a void in the network and referral system for mental health and domestic violence cri	1	1
<input type="radio"/>	<input type="radio"/> Provider's perception of IM rate des not match statistics	1	2
<input type="radio"/>	<input type="radio"/> Providers that are mentors and provide support and resources thoroughout the pregnancy even if specific	1	1
<input checked="" type="checkbox"/>	<input type="radio"/> Providers that are relevant in providing prenatal care in the area for Hispanics	4	17
<input type="radio"/>	<input type="radio"/> Indiana Health Department is not a medical provider, they only do referrals	1	1
<input type="radio"/>	<input type="radio"/> Providers think that prenatal care is not high priority in other cultures	1	1
<input checked="" type="checkbox"/>	<input type="radio"/> Providing education and care in a group setting	3	3
<input type="radio"/>	<input type="radio"/> Prenatal group and parenting group used to happen but have stopped due to lack of providers for it to	1	1
<input type="radio"/>	<input type="radio"/> Setting clear expectations about prenatal care so that patients understand how the system works	3	3
<input type="radio"/>	<input type="radio"/> Sleeping in the same bed with baby is a risky behavior commonly seen in the Latino community	4	9
<input type="radio"/>	<input type="radio"/> Subpopulation of Venezuelans clash with Mexicans beause of difference in access to services	1	1
<input checked="" type="checkbox"/>	<input type="radio"/> Swaddling or over wrapping babies is a cultural belief among Hispanics that can lead to IM	2	3
<input type="radio"/>	<input type="radio"/> Sometimes swaddling and overwrapping the baby is due to financial hardship, like no heating or lack of	1	1
<input checked="" type="checkbox"/>	<input type="radio"/> The influence of grandparents or other family members on unsafe practices	2	5
<input type="radio"/>	<input type="radio"/> Hispanic families do not talk openly about sex, so there is a lack of sex education	1	2
<input type="radio"/>	<input type="radio"/> The level of education within different ethnic groups in the Hispanic community influences their knowledg	3	7
<input type="radio"/>	<input type="radio"/> The level of stress and anxiety increases as the time gets closer to delivery, especially with a change in prov	1	1
<input type="radio"/>	<input type="radio"/> The process of providing care in the language that is needed requieres time and energy and provides pref	1	1
<input type="radio"/>	<input type="radio"/> The Venezuelan population has a different document status and therefore has more access to insurance an	2	3
<input type="radio"/>	<input type="radio"/> The Venezuelan population has a high c-section delivery rate, and it is difficult to convince them to have a	1	1
<input type="radio"/>	<input type="radio"/> There is a general perception that obstetrics does not make money, therefore not hagh priority	1	1
<input type="radio"/>	<input type="radio"/> There is a great need for bilingual (Spanish-English) staff	2	5
<input type="radio"/>	<input type="radio"/> There is a lack of providers in general that do OB	3	4

## From Infant Mortality to Infant Vitality

Causes of IM in Hispanic community		0	0
Being overweight may affect the overall health of an expectant mother		2	2
Car accidents due to not using car seats correctly		1	1
Drug and alcohol use during pregnancy		1	1
Lack of attention to the child		1	2
Lack of knowledge about how to care for a baby		1	1
Overwrapping, overprotecting		1	2
Suffocation		2	3
Vaping and smoking during pregnancy		1	1
Women over 45 who get pregnant have high risk pregnancies		1	1
challenges and barriers faced in the Hispanic community		1	1
Child care is expensive		1	2
Extended work schedules and reduced clinic schedules		2	4
Lack of follow-up on fetal developmental issues		1	1
Lack of information about protection laws in spite of undocumented status		1	2
Language barrier		2	2
Legal status may not make services as available or affordable		1	1
Prenatal care is expensive		1	1
Prenatal care visits are very limited		1	11
Common places to receive prenatal care		0	0
Hart City Health, Elkhart		2	7
Hospital in Elkhart		1	1
Maple City Health Care in Goshen		1	2
Definition of infant mortality		1	1
Crib Death		1	1
quantity of infant deaths		2	3
Feelings about infant mortality in the community		1	5
IM must be distinguished carefully from negligence or murder		1	1
Infant mortality is not normally seen in the Hispanic community		1	1
Infant mortality can be prevented		1	1
Infant mortality is a serious issue		2	9
Once the harm is done there is no way of fixing an infant death.		1	3

## From Infant Mortality to Infant Vitality

<input type="radio"/>	Participants demonstrated limited knowledge about obstetric warning signs		1	1
<input type="checkbox"/>	Protective factors against IM		0	0
<input type="radio"/>	An expectant mother should avoid self medicating		1	1
<input type="checkbox"/>	breastfeeding		1	4
<input type="radio"/>	Breast feeding is sometimes impossible due to lack of time (working mothers)		1	2
<input type="radio"/>	Some women are unable to breastfeed due to lack of milk		1	2
<input type="radio"/>	Careful medical monitoring of expectant mothers and birth		1	3
<input type="radio"/>	Early prenatal care is important to avoid IM		1	2
<input type="radio"/>	Eating healthy		1	1
<input type="radio"/>	Enough sex education at school or at home		1	1
<input type="radio"/>	Healthy relationship within the couple (parents)		2	2
<input type="radio"/>	Information about resources for pregnant women		1	2
<input type="radio"/>	Information on a safe pregnancy, post partum, and keeping children safe		2	8
<input type="radio"/>	Participants demonstrated general knowledge about preterm and term births		2	4
<input type="radio"/>	Participants manifest to be well informed about the pre natal care process and felt like their question		1	3
<input type="radio"/>	Prenatal vitamins and medications		1	1
<input type="radio"/>	Regular prenatal care is very important for a healthy pregnancy		2	3
<input type="radio"/>	Spanish-speaking organizations could help reduce Infant Mortality for Spanish speakers		1	1
<input type="radio"/>	Staying active during pregnancy helps to have a healthy baby		1	1
<input type="radio"/>	Trusting doctors and specialists give the family peace of mind		1	2
<input type="checkbox"/>	Reasons for high IM in 46514 and 46516		0	0
<input type="radio"/>	Excess confidence		1	1
<input type="radio"/>	Lack of education		1	2
<input type="radio"/>	Lack of information		2	5
<input type="radio"/>	neglect		2	2
<input type="radio"/>	Underage pregnancy		1	1
<input type="radio"/>	Unexplainable reasons		1	1
<input type="checkbox"/>	Resources in the community for expectant mothers and their families		1	1
<input type="checkbox"/>	Womens Care Center helps with parenting classes, diapers, coupons		1	2
<input type="radio"/>	Educational resources from Womens Care Center have positively influenced knowledge and perc		1	2

## From Infant Mortality to Infant Vitality

Name	Sources	References	Created By
Barriers to healthcare		0	0 IZ
Cost of healthcare		0	0 IZ
Elevated cost of specialist appointments		1	4 IZ
Health insurance		1	4 IZ
Going to places not covered by insurance		1	1 IZ
High frequency elevated cost medical appointments		1	4 IZ
Other already existent expenses		1	1 IZ
cultural differences		1	2 IZ
difficulty following indications given by the medical provider		1	6 IZ
providers do not ensure understanding of instructions		1	4 IZ
Not enough help is being provided to the mothers		2	3 IZ
Lack of transportation		1	2 IZ
Not feeling heard		1	2 IZ
Careless providers		1	5 IZ
Schedules		1	1 IZ
Unawareness of pregnancy		1	1 IZ
Characteristics of a healthy pregnancy		0	0 IZ
Nutrition		2	3 IZ
Physical activity		1	1 IZ
Prenatal care		2	5 IZ
Frequency of medical check-ups		2	3 IZ
Start of prenatal appointments		2	5 IZ
Support		1	1 IZ
Agencies		1	2 IZ
Use of community resources		1	3 IZ
Health Education		1	3 IZ
Partner		1	1 IZ
Emotional support		1	1 IZ
Financial support		1	2 IZ

Name	Sources	References	Created By
Financial stress		1	1 IZ
Nutrition		2	5 IZ
Overall health of the mother		1	2 IZ
gestational diabetes		2	4 IZ
obesity		1	2 IZ
Preterm babies		2	3 IZ
Characteristics of preterm babies		2	3 IZ
Reproductive health education		1	1 IZ
Tobacco and alcohol use		2	5 IZ
Unsafe sleep practices		1	1 IZ
Co-sleeping		2	10 IZ
Restrains like blankets		2	7 IZ
Sleeping positions		2	6 IZ
Unsureness about sleep practices		2	4 IZ
Use of pacifiers		2	6 IZ
Weight of the mother		1	1 IZ
Perceived impact of infant mortality in Elkhart		1	4 IZ
Perceived needed improvements		1	2 IZ
Information needs to be displayed according to the patients level of medical literacy		1	1 IZ



## APPENDIX G: SUMMARY STATISTICAL RESULTS OF SURVEY

	High School & Church Health Fairs 2 events Jun & Sep 2024 (N= 162)	Flu Shot Clinics 26 events Oct & Dec 2024 (N= 259)	Outreach Activities 3 events Aug & Sep 2024 (N=90)	Total (N=511)
<b>Age, n (%)</b>				
Under 18	17 (10)	0 (0)	0 (0)	17 (3)
18-24	1 (1)	35 (14)	10 (11)	46 (9)
25-34	44 (27)	66 (25)	35 (39)	145 (28)
35-44	42 (26)	44 (17)	25 (28)	111 (22)
45-54	18 (11)	61 (24)	6 (7)	85 (17)
55-64	5 (3)	20 (8)	4 (4)	29 (6)
65 and over	5 (3)	11 (4)	2 (2)	18 (3)
Prefer not to answer	30 (19)	22 (8)	8 (9)	60 (12)
<b>Gender Identity, n (%)</b>				
Women	113 (70)	148 (57)	47 (52)	308 (60)
Men	36 (22)	109 (42)	43 (48)	188 (37)
Prefer not to answer	13 (8)	2 (1)	0 (0)	15 (3)
<b>Race or Ethnicity (Check all that apply), n (%)</b>				
Hispanic or of Spanish origin	159 (98)	221 (85)	87 (97)	467 (91)
Not Hispanic or of Spanish origin	3 (2)	38 (15)	3 (3)	44 (9)
<b>Language Proficiency, n (%)</b>				
Spanish	147 (91)	195 (75)	80 (89)	422 (82)
English	10 (6)	63 (24)	5 (6)	78 (16)
Both	5 (3)	1 (1)	5 (6)	11 (2)
Prefer not to answer	0 (0)	0 (0)	0 (0)	0 (0)
<b>Geographic Location, ZIP Code, n (%)</b>				
46514	44 (27)	35 (14)	11 (12)	90 (18)
46516	19 (12)	49 (19)	19 (21)	87 (17)
46526	45 (28)	31 (12)	12 (13)	88 (17)
46528	41 (25)	10 (4)	6 (7)	57 (11)
46517	3 (2)	42 (16)	5 (6)	50 (10)
Other	4 (3)	92 (35)	8 (9)	104 (20)
Prefer not to answer	6 (4)	0 (0)	29 (32)	35 (7)

	High School & Church Health Fairs 2 events Jun & Sep 2024 (N= 162)	Flu Shot Clinics 26 events Oct & Dec 2024 (N= 259)	Outreach Activities 3 events Aug & Sep 2024 (N=90)	Total (N=511)
<b>Geographic Location, County, n (%)</b>				
Elkhart	155 (96)	228 (88)	55 (61)	438 (86)
Other	1 (1)	31 (12)	6 (7)	38 (8)
Prefer not to answer	6 (3)	0 (0)	29 (32)	35 (6)
<b>Geographic Location, Township, n (%)</b>				
Concord	66 (41)	126 (49)	36 (40)	228 (45)
Elkhart	86 (53)	67 (26)	18 (20)	171 (33)
Other	10 (6)	66 (25)	36 (40)	112 (22)
<b>Q1: What does the term infant mortality mean to you? (Mark only one), n (%)</b>				
A miscarriage	14 (9)	31 (12)	11 (12)	56 (11)
An abortion	12 (7)	23 (9)	16 (18)	51 (10)
The death of a baby at birth	17 (10)	38 (15)	7 (8)	62 (12)
The death of a baby or child (younger than 18)	26 (16)	54 (21)	24 (27)	104 (20)
The death of an infant (<1)	70 (43)	81 (31)	27 (30)	178 (35)
I don't know	23 (14)	32 (12)	5 (6)	60 (12)
<b>Q2: What do you think are the major causes of infant mortality in Elkhart? (Mark all that apply), n (%)</b>				
Birth defects	53 (18)	56 (14)	26 (17)	135 (16)
Premature birth/low birth weight	60 (20)	68 (17)	31 (21)	159 (19)
Health complications mother during pregnancy	69 (23)	96 (24)	33 (22)	198 (23)
Unsafe sleep practices (SIDS/SUIDs)	54 (18)	51 (13)	30 (20)	135 (16)
Assault/Injuries	35 (12)	35 (9)	17 (11)	87 (10)
I don't know	30 (10)	88 (22)	14 (9)	132 (16)
<b>Q3: For a healthy pregnancy and baby, we need to think about __ (Mark all that apply), n (%)</b>				
Nutrition	136 (15)	170 (14)	51 (16)	357 (15)
Prenatal care/checkups during pregnancy	131 (14)	220 (19)	54 (17)	405 (17)

	High School & Church Health Fairs 2 events Jun & Sep 2024 (N= 162)	Flu Shot Clinics 26 events Oct & Dec 2024 (N= 259)	Outreach Activities 3 events Aug & Sep 2024 (N=90)	Total (N=511)
Age of mother at pregnancy	63 (7)	69 (6)	14 (5)	146 (6)
Not drinking	119 (13)	143 (11)	38 (12)	300 (12)
Not smoking	118 (12)	151 (12)	46 (15)	315 (13)
Mothers' mental health	82 (9)	103 (9)	24 (8)	209 (9)
Mothers' weight	57 (6)	67 (6)	17 (5)	141 (6)
Breastfeeding	59 (6)	82 (7)	23 (7)	164 (7)
Sleep Habits	78 (8)	85 (8)	17 (5)	180 (7)
Controlling mothers' health condition (diabetes, hypertension, obesity)	88 (10)	126 (10)	27 (9)	241 (10)

**Q4: When I think about taking care of a baby and/or keeping them safe in this country and especially in Indiana, my main concerns are \_\_ (Mark all that apply), n (%)**

Not enough food	63 (10)	91 (12)	23 (10)	177 (11)
Can't afford clothing/baby supplies	35 (5)	48 (6)	14 (6)	97 (6)
Unsafe/inadequate housing	53 (8)	65 (9)	22 (9)	140 (8)
Don't speak English	40 (6)	30 (4)	15 (6)	85 (5)
Don't have health insurance/Medicaid	124 (19)	169 (23)	62 (26)	355 (22)
Don't understand the health system	37 (6)	43 (6)	10 (4)	90 (6)
No transportation	29 (5)	16 (2)	8 (3)	53 (3)
Inflexible work hours	36 (6)	48 (6)	12 (5)	96 (6)
Can't afford doctors' visits	77 (12)	99 (13)	18 (8)	194 (12)
I am new in this country	46 (7)	29 (4)	17 (7)	92 (6)
Don't have a doctor	67 (10)	56 (8)	23 (10)	146 (9)
Little or no support from family and friends	37 (6)	48 (6)	14 (6)	99 (6)

**Q5 and Q6: If someone told you the highest infant mortality rate among Hispanics was in Elkhart County, Indiana, would you believe it? n (%)**

Yes	51 (31)	73 (28)	41 (46)	165 (32)
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	High School & Church Health Fairs 2 events Jun & Sep 2024 (N= 162)	Flu Shot Clinics 26 events Oct & Dec 2024 (N= 259)	Outreach Activities 3 events Aug & Sep 2024 (N=90)	Total (N=511)
No	111 (69)	156 (60)	45 (50)	312 (61)
Don't know	0 (0)	26 (10)	4 (4)	30 (6)
Prefer not to answer	0 (0)	4 (2)	0 (0)	4 (1)

**Q7: For a successful pregnancy and healthy baby, my life would be easier with \_\_\_ (Mark all that apply), n (%)**

Financial Stability	109 (14)	150 (17)	31 (14)	290 (15)
Safe/stable housing	91 (12)	103 (11)	25 (11)	219 (11)
Strong family/friends support	58 (7)	79 (9)	23 (10)	160 (8)
Health insurance/Medicaid	118 (15)	150 (17)	35 (15)	303 (16)
A job	51 (7)	76 (8)	20 (9)	147 (8)
Better understanding of the health system	49 (6)	56 (6)	14 (6)	119 (6)
Transportation	39 (5)	41 (5)	11 (5)	91 (5)
Manageable work hours	38 (5)	47 (5)	16 (7)	101 (5)
Migrant status resolved	32 (4)	19 (2)	5 (2)	56 (3)
Fluent in English	44 (6)	28 (3)	14 (6)	86 (5)
Access to health care services	100 (13)	99 (11)	21 (9)	220 (12)
Access to educational programs	54 (7)	60 (7)	12 (5)	126 (7)

**Q8: I think in this area (Elkhart Co.), we need more places that offer information/services on the following topics \_\_\_ (Mark all that apply), n (%)**

Sex Education	105 (25)	103 (20)	24 (17)	232 (21)
Preconception health	93 (22)	104 (20)	26 (18)	223 (21)
Prenatal care	69 (16)	104 (20)	30 (21)	203 (19)
Postpartum mental health	78 (18)	104 (20)	27 (19)	209 (19)
Well-child visits	77 (18)	105 (20)	35 (25)	217 (20)

**Q9: What communications channels do you think would be more appealing to the Hispanic community to promote prevention health campaigns? (Mark all that apply), n (%)**

Facebook	126 (20)	140 (21)	45 (23)	312 (21)
What's App	71 (11)	65 (10)	19 (10)	155 (10)

	High School & Church Health Fairs 2 events Jun & Sep 2024 (N= 162)	Flu Shot Clinics 26 events Oct & Dec 2024 (N= 259)	Outreach Activities 3 events Aug & Sep 2024 (N=90)	Total (N=511)
Bus advertisements	41 (7)	41 (6)	15 (8)	97 (6)
Billboards	39 (6)	31 (5)	9 (5)	79 (5)
Radio	66 (11)	73 (11)	18 (9)	157 (10)
TV	58 (9)	66 (10)	22 (11)	146 (10)
Brochures/Pamphlets	37 (6)	45 (7)	16 (8)	98 (6)
Videos	45 (7)	43 (6)	14 (7)	102 (7)
NIHHC website	36 (6)	47 (7)	13 (7)	96 (6)
In person educational event	68 (11)	82 (12)	20 (10)	170 (11)
Online webinar	27 (4)	24 (4)	5 (3)	56 (4)
Podcast	4 (1)	2 (0)	2 (1)	8 (1)
Pandora	8 (1)	13 (2)	2 (1)	23 (2)
<b>Q10: Do you know what Emergency Medicaid is? n (%)</b>				
Yes	72 (44)	120 (46)	62 (69)	254 (49)
No	86 (53)	111 (43)	25 (28)	222 (44)
Prefer not to answer	4 (3)	28 (11)	2 (3)	36 (7)
<b>Q11: Do you know what the WIC Office is? n (%)</b>				
Yes	72 (44)	121 (47)	48 (54)	241 (47)
No	86 (53)	93 (36)	37 (42)	216 (43)
Prefer not to answer	4 (2)	45 (17)	4 (4)	53 (10)
<b>Q12: How satisfied are you with the health care services you have received in the Elkhart County area? n (%)</b>				
Very satisfied =3	70 (43)	96 (37)	27 (30)	193 (38)
Somewhat satisfied =2	45 (28)	68 (26)	21 (23)	134 (26)
Not satisfied =1	25 (15)	14 (5)	7 (8)	46 (9)
Prefer not to answer	22 (14)	81 (31)	35 (39)	138 (27)
<b>Q13: Where have you gone for medical services? (Write in), n (%)</b>				
Write in	30 (19)	18 (7)	29 (32)	78 (15)
Prefer not to answer	132 (81)	241 (93)	61 (68)	438 (85)
<b>Q14 If you or your partner were expecting a baby, where would you feel comfortable receiving prenatal care services? (Mark all that apply), n (%)</b>				
Maple City	52 (20)	41 (15)	13 (14)	106 (17)
Heart City	36 (14)	43 (16)	22 (24)	101 (16)

	<b>High School &amp; Church Health Fairs 2 events Jun &amp; Sep 2024 (N= 162)</b>	<b>Flu Shot Clinics 26 events Oct &amp; Dec 2024 (N= 259)</b>	<b>Outreach Activities 3 events Aug &amp; Sep 2024 (N=90)</b>	<b>Total (N=511)</b>
RETA	7 (3)	5 (2)	4 (4)	16 (3)
Women’s Care Center	31 (12)	29 (11)	16 (17)	76 (12)
Goshen Physician OB/GYN	44 (17)	59 (21)	14 (15)	117 (19)
Goshen Physician Family Medicine with OB Pro Park	40 (16)	41 (15)	6 (7)	87 (14)
Beacon Medical Group Obstetrics & Gynecology Elkhart	44 (17)	57 (21)	17 (18)	118 (19)



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