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Community perspectives on the health information ecosystem

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Abstract

The COVID-19 infodemic highlighted how misinformation, inconsistent guidance, and barriers to reliable information undermined vaccine confidence, particularly in underserved communities. This qualitative study examined barriers to vaccination, as well as communication and information challenges experienced by community residents and stakeholders in areas of high social vulnerability in a mid-sized Midwestern city. Focus groups and interviews with community residents, community leaders, and healthcare providers (N = 31) were thematically analysed and interpreted through the Social Ecology of Health Beliefs and Misinformation Framework. Findings identified two primary themes: (1) barriers to vaccination and (2) communication and information challenges, including language barriers and a lack of reliable information. These challenges emerged across individual, interpersonal, community, and structural/systemic levels. Community-informed solutions included micro-communication through trusted community messengers, culturally congruent communication, and partnerships with faith organisations. Importantly, these findings have implications for future public health crises, highlighting the need for coordinated strategies that operate across ecological levels and emphasise clear, culturally relevant, and trusted health messaging. Strengthening trusted messenger networks, fostering community partnerships, and implementing policies that address inequities may improve preparedness for future public health crises.

Introduction

Despite longstanding efforts to eliminate vaccine-preventable diseases (Centers for Disease Control and Prevention [CDC], 2026), recent outbreaks highlight ongoing challenges in vaccination and public health communication. For instance, 2,289 measles cases were recorded in 2025, and by October 2026, that number had already been surpassed, with 3,887 confirmed cases nationwide (CDC, 2026). Among these cases, 95% occurred among individuals who were unvaccinated or had unknown vaccination status, and 352 resulted in hospitalizations (CDC, 2026). These increases disproportionately burden socioeconomically challenged and medically underserved communities facing transportation, healthcare access, cost, and language barriers (Adeoye et al., 2025). Racial disparities in vaccination coverage further compound this vulnerability, as Black and American Indian/Alaska Native children have lower measles vaccination rates than White children (Hill et al., 2025). This resurgence is particularly alarming given the decades of empirical evidence demonstrating the safety and effectiveness of measles vaccination (Di Pietrantonj et al., 2021).

Credible health information is “consistent with the best scientific evidence available at the time” (Burstin et al., 2023). In contrast, misinformation is commonly defined as “information that is incorrect or false in the context of scientific understanding of the times” (Kenen et al., 2025). Misinformation remains a key driver of declining vaccine confidence (Hijano et al., 2025; Kiang et al., 2025). One of the most persistent examples is the claim that the measles vaccine causes autism, despite overwhelming scientific evidence to the contrary (Anson & Patel, 2026). Beyond the spread of misinformation, individuals must also navigate increasingly complex information environments. An infodemic, defined as an abundance of

information, both credible and false, can create additional challenges for vaccine adherence (Kisa & Kisa, 2024).

Lessons Learned from the Infodemic During the COVID-19 Pandemic

One critical issue that emerged during the COVID-19 pandemic was the “infodemic,” within which misinformation amplified through social media competed directly with evidence-based public health guidance (Kisa & Kisa, 2024). Despite evidence supporting vaccine safety and effectiveness (Liu et al., 2021), pieces of misinformation made it difficult to distinguish reliable guidance from misleading claims, further widening gaps in equitable protection for underserved communities (Ratnayake et al., 2024). This pattern extends beyond COVID-19, as the current measles resurgence demonstrates that misinformation remains a threat across public health crises (Kiang et al., 2025).

Despite lessons learned from the COVID-19 infodemic (Burstin et al., 2023; Kisa & Kisa, 2024), recurring outbreaks of vaccine-preventable diseases, such as measles (CDC, 2026), suggest that many lessons have yet to be fully implemented. Understanding how underserved communities navigate complex health information environments and what solutions they recommend may help inform communication and preparedness efforts during future public health crises. This study draws on focus groups and interviews with residents, community leaders, and healthcare providers in a mid-sized Midwestern city where more than half of the residents live in areas of high social vulnerability (CDC Agency for Toxic Substances and Disease Registry [ATSDR], 2024), providing community perspectives on barriers to vaccination, communication and information challenges, and community-informed solutions. Guided by the Social Ecology of Health Beliefs and Misinformation Framework (SEHBMF) (Enyinnaya et al., 2024), this exploratory qualitative study examined barriers to vaccination, as well as communication and information challenges, experienced by underserved communities during the COVID-19 pandemic, and identified strategies to address these challenges in future public health crises. This study aimed to answer the following research questions:

1) What barriers to vaccination, and what communication and information challenges, are experienced by community residents and stakeholders in areas of high social vulnerability?

2) What solutions do participants recommend to address barriers to vaccination, as well as communication and information challenges, during future public health crises?

Methods

Theoretical Framework

This study was grounded in the SEHBMF, which integrates the Social Ecological Model (SEM) and Health Belief Model (HBM) to examine how misinformation and information environments shape health beliefs and vaccine decision-making (Enyinnaya et al., 2024). The SEM conceptualizes health behaviours as

being shaped by interactions across multiple levels, including individual, interpersonal, community, and broader structural/systemic factors (Dickens et al., 2025; Kilanowski, 2017). The HBM focuses on how individuals' beliefs shape health decision-making through constructs such as perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action (Alyafei & Easton-Carr, 2024). The SEM informed the focus group protocol and organisation of findings across ecological levels (Dickens et al., 2025; Kilanowski, 2017), while the HBM informed the interpretation of participants' vaccination beliefs (Alyafei & Easton-Carr, 2024). Together, these models guided analysis of vaccine decision-making and opportunities for intervention (Enyinnaya et al., 2024).

Study Design

This qualitative study was conducted as part of a collaborative initiative among local government, community partners, and academic institutions to promote COVID-19 awareness, vaccine uptake, and health literacy in a mid-sized Midwestern city. This study was approved by the University's College of Medicine Institutional Review Board.

The study focused on three adjacent zip codes in which more than half the residents lived in areas of high social vulnerability, as measured by the Centers for Disease Control and Prevention's Social Vulnerability Index (SVI ≥ 0.90) (CDC ATSDR, 2024). These communities also accounted for the largest proportions of African American/Black residents (32.37%) and Hispanic/Latino residents (23.45%) in the city (U.S. Census Bureau, n.d.). They also experienced higher COVID-19 case rates and lower vaccination uptake (Rockford Register Star, 2022), highlighting the need to understand barriers to vaccination, as well as communication and information challenges.

Participant Recruitment

Participants were recruited through a community task force composed of principal investigators, faith leaders, Latino and African American community representatives, a regional health council director, and staff from the city's Office of Health and Human Services. Purposive recruitment was used to ensure representation from community residents, healthcare providers, and community leaders connected to the target communities. Recruitment occurred through community-based outreach, referrals, and partnerships with community, faith, and professional organisations. Task force members and community leaders identified eligible participants and distributed study information.

Eligible participants were adults (≥ 18 years) who lived in, worked in, or served individuals in the three target zip codes. A total of 31 participants took part in the study: 26 across five focus groups and five Spanish-speaking residents who completed individual interviews due to scheduling conflicts. Community residents received $20 Walmart gift cards for their participation, while healthcare providers and community leaders were not compensated.

Focus Groups and Interviews

Experienced bilingual facilitators conducted all focus groups and interviews in accordance with established qualitative methods (Krueger & Casey, 2009). A total of five focus groups were conducted across three participant types (n = 26): community residents, community leaders, and healthcare providers. Three of the five focus groups were with community residents (n = 13) and explored attitudes toward and experiences with COVID-19 and vaccination, as well as challenges in obtaining information. These groups were stratified by vaccination status and age. The fourth focus group was with community leaders (n = 6), including representatives from faith organisations, community service agencies, and other local programmes, and explored community perspectives on COVID-19, access to vaccination, and willingness to be vaccinated. The fifth and final focus group was with healthcare providers (n = 7) and explored perspectives on barriers to vaccination and health information within the community. Five Spanish-speaking residents (n = 5) completed individual interviews using the same semi-structured protocol. Table 1 presents the demographics of focus group and interview participants.

Table 1
Focus Group and Interview Participant Demographic Characteristics

Group	Type of Participant	Number of Participants	Demographic Characteristics
Focus Group #1 (FG1)	Vaccinated Individuals (30–49 years)	4	3 females; 1 male
Focus Group #2 (FG2)	Vaccinated Individuals (50 + years)	5	5 females
Focus Group #3 (FG3)	Unvaccinated Individuals	4	3 females; 1 male
Focus Group #4 (FG4)	Community Leaders	6	3 African American; 2 White; 1 Hispanic/Latino
Focus Group #5 (FG5)	Healthcare Providers	7	Predominantly White; 1 identified as Latina
Spanish-speaking Interviews	Community Residents	5	3 females; 2 males

Note: This project was conducted as a quality improvement initiative. Race/ethnicity data were not collected for community resident focus groups (FGs 1, 2, and 3) or interviews with Spanish-speaking community residents. Sex data were not collected for the community leader and healthcare provider focus groups (FGs 4 and 5). Vaccination status data were not collected for community leader and healthcare provider focus groups (FGs 4 and 5) or for interviews with Spanish-speaking community residents.

Data Collection

Data collection occurred between November 2021 and July 2022. Focus groups and interviews were guided by a semi-structured protocol that explored how underserved communities perceived health information during the COVID-19 pandemic and how communication could be improved in future outbreaks. Specifically, the questions explored barriers to vaccination, as well as communication and information challenges, including language barriers and a lack of reliable information. Participants also provided recommendations for improving communication and access during future public health crises.

Data Analysis

All focus groups and interviews were audio-recorded and transcribed verbatim. Interviews conducted in Spanish were first transcribed verbatim in Spanish and subsequently translated into English for analysis. Participant quotations are presented verbatim to preserve participants' voices and perspectives. Ellipses indicate omitted text for brevity without altering the meaning of participants' statements. Two team members independently coded transcripts using a hybrid deductive-inductive approach. Initial codes reflected the major topics in the discussion guide, while additional codes were developed and refined based on patterns that emerged in the data and relevant literature. Codes were then organized into primary themes and supporting quotations (Braun & Clarke, 2006; Miles et al., 2020). Intercoder agreement between the primary coders reached 95%, with a third team member resolving discrepancies through discussion.

Following thematic analysis, data were organized using the SEHBMF, which integrates SEM and HBM (Enyinnaya et al., 2024). SEM coding categorized information challenges according to the ecological level at which they occurred (individual, interpersonal, community, or structural/systemic) (Kilanowski, 2017). In contrast, HBM coding identified belief constructs that shape decision-making (perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action) (Alyafei & Easton-Carr, 2024). This approach enabled examination of how themes and subthemes manifested across ecological levels, as well as how health beliefs influenced information navigation and vaccine decision-making. Peer debriefing verified coding decisions, with discrepancies resolved through discussion until consensus was reached.

Results

Two primary themes emerged from the qualitative analysis: (1) barriers to vaccination and (2) communication and information challenges. Within the communication and information challenges, two subthemes emerged: language barriers and lack of reliable information. Because misinformation emerged as a central concern across participant groups, findings related to the lack of reliable information are examined in greater depth. Themes and subthemes are examined across individual, interpersonal, community, and structural/systemic levels.

Barriers to Vaccination

Barriers to vaccination emerged as a central theme across all groups. Participants described challenges across individual, community, and structural/systemic levels, whereas no distinct interpersonal-level barriers emerged from the data. *At the individual level*, fear and uncertainty functioned as perceived barriers, including concerns about vaccine safety and unknown side effects. *At the community level*, barriers to access and resource distribution included technological challenges that disproportionately affect vulnerable groups, difficulty locating vaccination sites, and the need to navigate frequently changing information about vaccine availability. Participants also emphasised the need for proactive, community-centred approaches, such as mobile units and door-to-door outreach. *At the structural/systemic level*, vaccination barriers were linked to institutional mistrust and inconsistent messaging. One healthcare provider suggested that vaccine mandates increased resistance to vaccination: “I also believe that by some states or health systems making a mandate for vaccination is refusing more people to vaccinate. It's a negative approach to the vaccine” (FG5, healthcare provider).

Communication and Information Challenges

Communication and information challenges emerged across all five focus groups, with participants describing gaps, inconsistencies, and barriers in how COVID-19 information was communicated. *At the individual level*, participants reported difficulty understanding complex, technical information and the need for communication tailored to varying health literacy levels. *At the interpersonal level*, participants described communication barriers during patient-provider interactions, including feeling unheard and having limited opportunities to ask questions about vaccination. *At the community level*, residents highlighted the lack of centralized communication channels for locating testing and vaccination resources, with one participant noting the need for “some kind of forum or outlet for people with different opinions and different perspectives to come together and talk about solutions” (FG3, unvaccinated community resident). *At the structural/systemic level*, participants described confusion arising from rapidly changing guidance, inconsistent information, and limited dissemination systems for communicating public health resources. Within this broader theme, two subthemes emerged: language barriers and lack of reliable information.

Language Barriers. Language barriers emerged as a subtheme across individual, interpersonal, community, and structural/systemic levels. *At the individual level*, understanding health information was influenced by health literacy. One community resident noted, “Their health literacy level could impact their understanding of the information they receive” (FG1, vaccinated community resident). *At the interpersonal level*, Spanish-speaking residents described relying on bilingual family members and friends as cues to action, helping them schedule appointments, interpret information, and communicate with healthcare providers. As one resident explained, “I got my 3 vaccines from the Walgreens pharmacy with the help of my dear friend… She speaks English, you see, I do not. I only speak Spanish. She speaks for me and she helped me” (Interview, Spanish-speaking community resident). *At the community level*, participants described limited availability of translated and linguistically appropriate materials. *At the structural/systemic level*, language barriers were linked to broader inequities and reliance on informal sources of information.

Lack of Reliable Information. Across all groups, participants described how the information ecosystem influenced vaccination attitudes across multiple levels.

At the individual level, two key findings included difficulty interpreting information and reliance on social media as a primary source. Participants described feeling overwhelmed by contradictory information about COVID-19 and vaccines, making it difficult to make informed decisions for themselves and their families. One resident described this confusion: “I think what makes it difficult is, again, misinformation, and also just the lack of education about efficacy versus safety… whether or not we’re gonna vaccinate ourselves, let alone our kids, and it’s very hard to figure out what’s what” (FG3, unvaccinated community resident). Uncertainty about which sources to trust often led participants to rely on social media, which many identified as a major source of misinformation. A Spanish-speaking resident described encountering false information online, explaining, “I think that people do not think the vaccine will help. They have information but it is wrong information they read from comments and posts online that say the vaccine is bad. But that is not the truth” (Interview, Spanish-speaking community resident). Participants reported that misinformation contributed to fear, mistrust, and conspiracy beliefs about vaccine safety. As one Spanish-speaking resident explained, “People do not trust the vaccine. I know that technology is advancing as well as science very quickly but we do not know if it is truly good or bad. The vaccine was released very rapidly so some thought a lot about the fact that they may be injecting microchips” (Interview, Spanish-speaking community resident). Despite these challenges, some participants described consulting multiple sources of information to make more informed decisions. As one resident explained, “The more you are informed from not just one particular side, it helps you. You make more of an educated decision” (FG3, unvaccinated community resident).

At the interpersonal level, two key findings included the role of micro-communication through trusted peer networks and the importance of culturally congruent messengers in delivering reliable information. Participants described how misinformation spread through informal social networks and online sources, undermining vaccine confidence. As a community resident stated, “People are listening to other people or the websites that people can Google and go on and encourage people not to take the vaccination… the latest thing I heard is that, because the government is getting paid every time somebody is vaccinated” (FG2, vaccinated community resident). Participants also identified trusted sources that could counter misinformation. One resident described reliance on their physician: “I would say that I have used my primary doctor… this is where we got the most information” (FG2, vaccinated community resident). Similarly, a community leader emphasised the importance of micro-communication through trusted neighbourhood networks, recommending, “Somebody in that neighborhood knows what's going on, and everyone trusts them… We have got to get down to that micro-communication level if we honestly want to communicate with everyone” (FG4, community leader). Participants also emphasised the importance of receiving information from culturally congruent messengers who share the identities and lived experiences of the communities they serve. As a healthcare provider suggested, “I think it could be helpful if the information is coming from other minorities and people like themselves” (FG5, healthcare provider).

At the community level, two key findings included community education needs and the role of faith organisations as trusted pathways for delivering reliable information. Participants described widespread misinformation within the community, often circulating through social media. As one community resident stated, “A lot of misinformation… Social media is a driving force nowadays. People check their phone on social media before they check anything else nowadays and there’s just so much misinformation. And it started pre-COVID. It started with all these other vaccines and – and it’s kind of scary” (FG3, unvaccinated community resident). In response to these concerns, participants emphasised the need for targeted community education to counter misinformation, particularly in communities with limited English proficiency. As one resident explained, “They said, ‘I will not take vaccination because I will not be able to make babies.’ Another one said, ‘No, I will have GPS in my body.’ Another one said, ‘No, it’ll change my DNA...’ We need to educate the community about this. We need knowledge. We need learning. That’s it. Simple” (FG1, vaccinated community resident). Healthcare providers similarly emphasised the need for consistent and accessible messaging to counter misinformation. Participants also identified faith organisations as trusted pathways for delivering reliable information. One resident noted, “I would suggest to start with the faith centers, either church or temples. I will trust any resource coming from my church because as moral faith and because of what I’m doing” (FG1, vaccinated community resident). Similarly, a community leader emphasised the importance of leveraging trusted community figures to counter misinformation.

At the structural/systemic level, two key findings were the impact of rapidly changing guidance on institutional trust and the role of historical trauma in shaping susceptibility to misinformation. Participants expressed frustration with rapidly changing guidance that undermined trust in public health institutions. One resident explained, “Today they said that the age is 12 and above. Suddenly, next day, oh no! It’s 15 to 12, so within a 24- hour change. Quarantine was 10 days. Next day… it is five days even though the same virus… They made it worse, so it’s just a matter of rush or unplanned directions” (FG1, vaccinated community resident). Participants also described how political polarization further eroded institutional trust. One resident noted, “Even in a pandemic, the – the political side of it being polarized – this view or that view. I think a lot of people really kind of got discouraged, not only with the government, but just with the medical system… I definitely know a lot of people that have struggled with that part of distrusting government and so forth” (FG3, unvaccinated community resident). In general, participants thought that health, especially a pandemic, should not be politicized because it increases mistrust. Beyond concerns about changing guidance and polarization, participants described how historical trauma contributed to mistrust and susceptibility to misinformation. A community leader explained, “The historical trauma … and different situations also feed into the notion of why people are… misinformed… and just the mistrust. Once you don’t trust something, it is hard to trust… If you don’t trust the government, it is hard for you to trust and hear the information they are giving you” (FG4, community leader). A Spanish-speaking resident described similar concerns: “In the beginning, a lot of people died without getting access to the right care… So, it was a lot of contradictory information, a lot of confusion, the information is not accurate with Immigration and those things” (Interview, Spanish-speaking community resident).

Discussion

Findings suggest that barriers to vaccination, as well as communication and information challenges,operated across ecological levels and shaped vaccine perceptions and decision-making. Within communication and information challenges, language barriers and lack of reliable information emerged as important subthemes. Participants also identified solutions concentrated at the interpersonal and community levels, including trusted messengers, culturally congruent communication, community education, and faith partnerships. With the resurgence of measles and persistent vaccination disparities, these findings have direct implications for managing current and future public health challenges. Applying the SEHBMF revealed that barriers emerged across all ecological levels, whereas community-informed solutions were concentrated at the interpersonal and community levels (Enyinnaya et al., 2024).

At the individual level, difficulty interpreting information and reliance on social media reflected broader communication failures rather than individual shortcomings. Contradictory messages, technical language, and evolving guidance made reliable information difficult to identify, increasing reliance on social media to navigate uncertainty. These findings underscore the importance of plain-language communication, contextualizing evolving guidance to build trust, and supporting health literacy to promote informed decision-making.

At the interpersonal level, micro-communication and culturally congruent messengers emerged as the most actionable strategies for countering misinformation. Prior work highlights the role of trained culturally competent community health workers in promoting vaccine uptake (Suarez-Balcazar et al., 2024), and trusted messengers can effectively deliver vaccine education when provided with appropriate tools and training (Caballero et al., 2023). These findings suggest that effective messengers may already be embedded within communities and simply need support and accurate information to share.

At the community level, education needs and the role of faith organisations highlighted how gaps in accessible health education create opportunities for misinformation to spread. Faith organisations emerged as particularly trusted intermediaries because of their moral authority, cultural alignment, and community reach. Prior studies similarly identify community-based organisations as important intermediaries for improving access to health information (Allen-Meares et al., 2024). Our findings extend this work by suggesting that faith institutions may represent an underutilized intervention point for delivering trusted health information.

At the structural/systemic level, rapidly changing guidance and historical trauma created conditions in which misinformation could thrive, and institutional messaging was met with justified skepticism. Participants described how shifting recommendations without proper explanation eroded trust and made it difficult to discern which information was reliable. Historical trauma further compounded these challenges, shaping perceptions of institutional credibility and amplifying skepticism. Overall, participants identified solutions primarily at the individual, interpersonal, and community levels to counter misinformation and strengthen communication. Notably, while participants described numerous

structural/systemic barriers, they identified few structural/systemic solutions. Nevertheless, the findings highlight the need for researchers and policymakers to advocate for structural reforms that acknowledge historical harm and address the conditions that allow misinformation to spread.

Preparing for a public health crisis requires a multi-level, comprehensive, and cohesive approach that builds on trusted community-level settings, including faith and community organisations, and on mechanisms for delivering information through reliable and trusted sources.

Limitations

This study has several limitations. Findings are drawn from a single mid-sized city, which may limit generalizability to other settings. Purposive community-based recruitment may have excluded the perspectives of some residents and community stakeholders. Data were collected during the COVID-19 pandemic and provide a snapshot of perceptions that may change as the information ecosystem evolves.

Although two major themes emerged, findings related to the lack of reliable information are presented in greater depth. The semi-structured interview protocol was not specifically designed to elicit policy or systems recommendations, which may have limited discussion of structural/systemic solutions. Finally, self-reported data may reflect recall bias or social desirability responses.

Despite these limitations, the study's strengths include its community-centred approach, diverse stakeholder perspectives, and the application of the SEHBMF, which provided a structured lens for examining how information challenges shaped vaccine decision-making across ecological levels.

Implications and Lessons Learned for Future Health Crises

Findings highlight the need for coordinated communication strategies across ecological levels and for health information to be presented in contextually relevant ways to strengthen preparedness for future public health crises. Clear, consistent, culturally relevant, and transparent communication may help ensure that information is accessible, actionable, and trusted by diverse communities.

At the individual level, public health communication should use plain language and explain evolving guidance. *At the interpersonal level*, trusted messengers, including community health workers, faith leaders, and other influential community members, should receive ongoing training and resources to counter misinformation. *At the community level*, partnerships with community-based organisations and faith institutions can strengthen education efforts and facilitate culturally congruent messaging. *At the structural/systemic level*, policymakers should address historical harm, language-based information inequities, and promote organisational health literacy practices.

Participants identified practical intervention points, including trusted community networks, culturally congruent messengers, faith partnerships, and clear, consistent communication. Translating these community-informed insights into sustained policy action and institutional investment is critical for

building an equitable health information ecosystem and strengthening preparedness for future health crises. As recurring outbreaks of vaccine-preventable diseases continue to challenge public health, these community-informed lessons offer practical guidance for addressing communication and information challenges during future public health crises.

Declarations

Competing Interests

The authors declare no competing interests.

Ethics Declaration

This study was reviewed and approved by the University of Illinois College of Medicine at Rockford Institutional Review Board (Protocol #21064). All methods were conducted in accordance with applicable University of Illinois policies and procedures governing human participant research. Informed consent was obtained from all participants.

Author Contribution

P.A.M., Y.S.B., and M.K. led the study, data collection, initial thematic analysis, and manuscript drafting. L.S. revisited the data to identify subthemes. All authors contributed to writing and reviewing the manuscript.

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Data Availability

Qualitative data are not publicly available due to confidentiality considerations. De-identified coded data may be available from the corresponding author upon reasonable request.

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Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- CommunityLeadersandHealthcareProvidersFocusGroupGuide.pdf
- CommunityResidentsFocusGroupGuide.pdf
- SpanishSpeakingPhoneInterviewGuide.pdf