

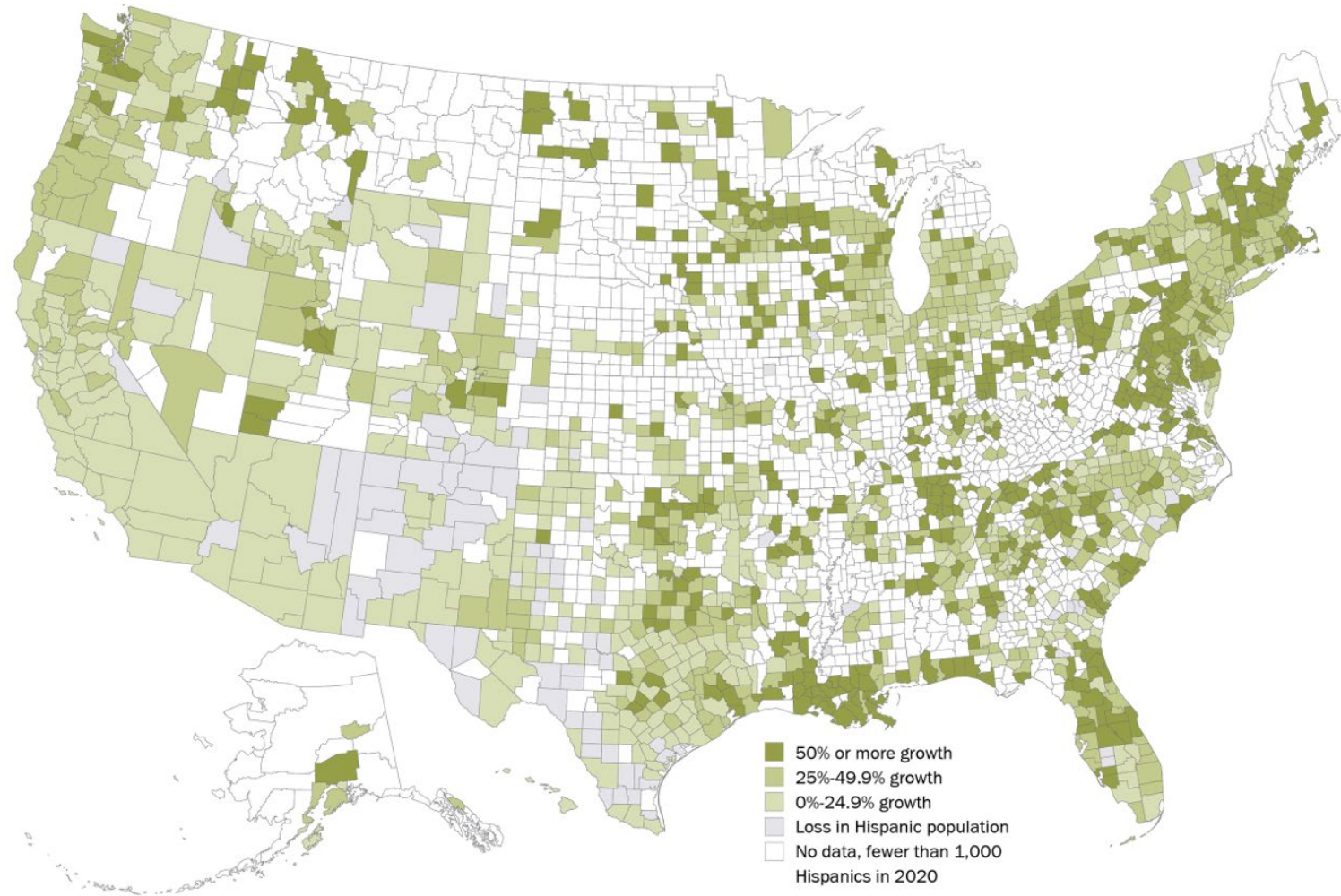
Acceptability of an AI Chatbot for Cancer Genetic Screening in Underserved Hispanic Populations in the Heartland

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Background

Hispanic population growth rates from 2010 to 2020 highest in states that historically did not have large Hispanic populations

% growth of Hispanics



Note: "Historical" Hispanic states are Arizona, California, Colorado and New Mexico (in the West), Illinois (Midwest), Florida and Texas (South), New Jersey and New York (Northeast). Growth rates not shown for counties with fewer than 1,000 Hispanics in the 2020 census.

Source: Pew Research Center tabulations of decennial census counts, P.L. 94-171.



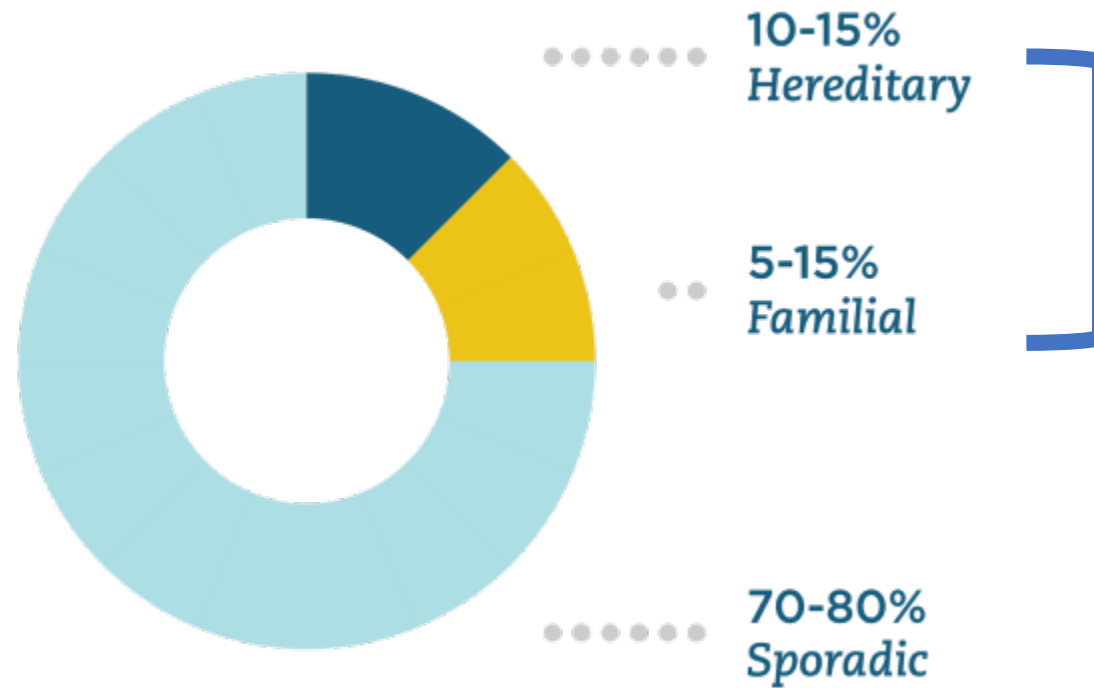
The leading cause of death for Hispanic adults is cancer

- Heart disease for nearly all other racial/ethnic groups (Centers for Disease Control and Prevention, 2017)
- Cancer death rate has declined in other racial/ethnic groups over time (Centers for Disease Control and Prevention, 2017)
 - Increased education
 - Innovations in treatment
 - Early detection and prevention (American Cancer Society, 2022)

Hispanic adults diagnosed at younger ages, with later stage diagnoses

- Median age at diagnosis of 30
 - 40 for NHW (Miller et al. 2021)
- Higher risk of advanced-stage diagnosis than NHW (Miller et al. 2021)
- 2nd most prevalent carriers of BRCA1/2 mutations (John et al. 2007)
- Awareness of genetic counseling and testing remains low (Rajpal et al. 2017)

Cancer genetic services can reduce cancer morbidity and mortality through identification and enhanced screening



Genetic services are limited

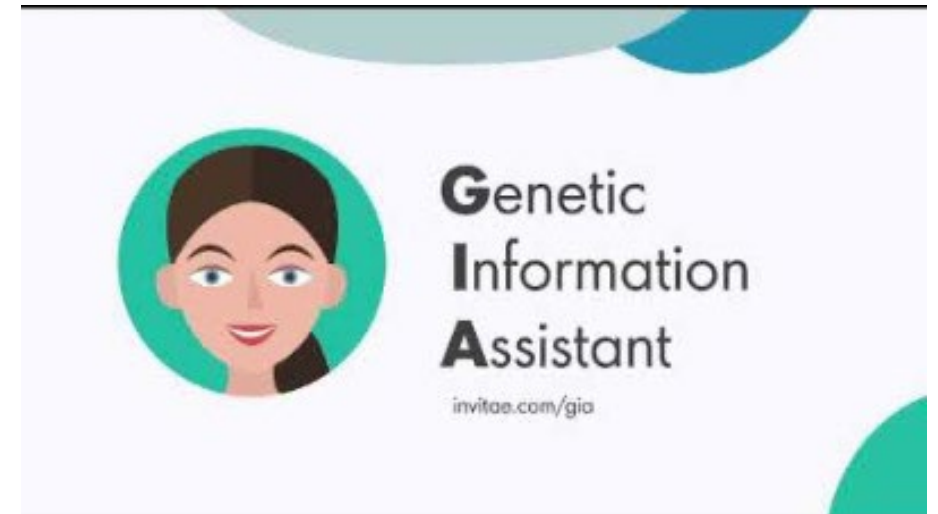
- In general
 - Shortage of genetic counselors expected to last until 2024-2030 (Hoskevec et al. 2018)
- In Spanish
 - PSS 2020: 4.16% speak Spanish
- In Spanish, in the Heartland
 - 2 Spanish-speaking, patient-facing cancer genetic counselors in the Heartland States (Basser Center for BRCA, 2019).
- Availability and quality of interpretation services is questionable (Hallford et al. 2020, Andreeva and Unger 2015, Blendon et al. 2015, Dahal et al. 2014)


Alternative service delivery models (ASDMs) can expand reach of cancer genetic counseling

- Telegenetics
 - No significant difference in satisfaction vs traditional setting for cancer GC (Binion et al. 2021)
- Pre-test educational tools
 - Culturally-targeted cancer GC educational video found useful, well-liked (Hurtado-de-Mendoza et al. 2019)
- Healthcare chatbots
 - Gia

What is Gia?

- Artificial intelligence (AI) chatbot that interacts with users in a text message-like style
- Developed and validated by genetic counselors
- Accessible on computer, tablet, or smartphone
 - 85% smartphone ownership, 25% smartphone-only internet users (Pew Research Center 2021)
- Available in English or Spanish
- Schmidlen et al. 2019: favorable impressions of Gia for genomic study consenting, cascade genetic testing





Community leaders are key collaborators for bringing innovations in healthcare to Hispanic communities

- Torres et al. 2016: help open communication, are trusted by community members for advice or counsel, have credibility in their communities
- Torres et al. 2016: help recruit community members in need of services or provide information about a project to their communities
- Research on Gia with cohorts comprised of individuals from more diverse ethnic backgrounds is valuable for ensuring equitable implementation of this technology, investigating if it ameliorates the barriers some genetic counselors have posited it might (Schmidlen et al. 2019; Nazareth et al 2021).
- “Nothing about us without us”



Study Aims

1. Investigate barriers to care in regional Hispanic communities
2. Assess health education approaches used by regional Hispanic community leaders
3. Evaluate acceptability of Gia amongst regional Hispanic community leaders

Barriers to care in regional Hispanic communities

- **Documentation status** is the largest barrier to care for regional Hispanic/Latinx populations (8/8)
- **Language barriers** impact families' abilities to navigate a predominantly English-language healthcare landscape (7/8)
- **Income and insurance** are top barriers for healthcare (7/8)
- **Competing priorities** lead to cancer prevention and preventative healthcare being set aside (7/8)
- There is an **increased need for education about cancer** in regional Hispanic/Latinx communities (8/8)
- Families are **interested in learning more about their cancer risks** (8/8), **with caveats** (6/8)
- An **increased need for literacy and baseline education** exists in some regional Hispanic/Latinx communities (6/8)
- **Awareness of existing cancer services and the U.S. healthcare system** are additional areas of need for regional Hispanic/Latinx communities (5/8)

Health education approaches used by regional Hispanic community leaders

- **Trust** is a motivator in health-seeking behavior for regional Hispanic/Latinx communities (7/8)
- **One-on-one education step-by-step** through a process is an effective educational method for Hispanic/Latinx adults (7/8)
- **A personal touch** is important when providing education to Hispanic/Latinx individuals (6/8)
- Providing education **in the target audiences' communities** is a core component of community leader education (6/8)
- **Simple language** is important (6/8)
- Resources and education should incorporate **different languages** (5/8)
- Resources should incorporate **colors and visuals** (5/8)

Methods



Inclusion Criteria

- Hispanic adults with a leadership role in their community
 - Translators, public health professionals, parent resource coordinators
- Who speak English or are bilingual in English and Spanish
 - Who can also read English and/or Spanish, OR have someone who can help them read English or Spanish



Recruitment

- Personal contact recruiting
 - Builds trust and enhances credibility with participants (Garcia et al. 2017; Torres et al. 2016)
 - More effective recruitment method than other research recruitment strategies (Zuñiga et al. 2014, Lagon et al. 2011, Garcia et al. 2015)
 - Bilingual genetic counselor/Heartland project coordinator recruited four participants
 - Two of those four participants recruited the remaining four participants



Interviews

- 2 interviews:
 - Pre-chatbot interview about access to care, educational methods, perceptions of cancer, familiarity with chatbots
 - Post-chatbot interview about experience with chatbot, acceptability and utility for regional Hispanic/Latinx communities
- Zoom or phone interviews, recorded and transcribed
- Questions synthesized from existing literature on chatbots in genetic counseling, barriers to cancer care in urban settings, and Oklahoman/Nebraskan access to pediatric genetic counseling



Data Analysis

- 2 independent coders reviewed and independently coded all transcripts, met to discuss possible themes
 - Intercoder reliability (by percent agreement): 94.2%
- Re-read transcripts to code for mutually agreed-upon themes, selected quotes to support themes
 - Grounded Theory
- Sub-themes used a 50% threshold

Results

Participant Demographics

Demographic	Number of Participants
Age	
35-39	1
40-44	1
45-49	2
50-54	4
Gender	
Female	8
Male	0
Non-binary	0
Preferred Language	
Spanish	8
English	0
Highest Level of Education Obtained	
High School Diploma	1
Associate's Degree	1
Bachelor's Degree	6
Family's Country of Origin	
Mexico	3
Costa Rica	1
Venezuela	1
Peru	1
Dominican Republic	1
Puerto Rico	1
Household Income	
\$50,000 to \$74,999	3
\$75,000 to \$99,999	3
\$100,000+	1

Participant Characteristics

Characteristic	Number of Participants
Frequency of Visits to Country of Origin	
Twice a year	3
Once a year	1
Every five years	1
Not very often	2
Familiar with Medical Portals?	
Yes	4
No	2
Maybe	2
Familiar with Chatbots?	
Yes	1
No	7
Gia Completed in English or Spanish?	
English	5
Spanish	3
Would Recommend Gia to Community Members	
Yes	8
No	0

Themes: Interview 2



Themes: Interview 2



All community leaders liked Gia (8/8), most described Gia as easy to use (7/8)

I like it. I like it. I think it was very simple, very easy. And very easy to...I mean, I didn't see any...any glitches, you know? I mean, it was really easy to connect. The link just take [sic] you to that chat, and... I just wasn't prepared. You know, I didn't really know what I was gonna do. I thought it was gonna be more like, like a survey. But it was interesting because I thought it was kind of like those pop-up chats that we get from, like from Home Depot or Amazon like "oh is that a live chat?" (P3)

I personally didn't find anything confusing, because I'm so used to WhatsApp, that I knew, I mean I saw that- I read the directions at the beginning and it said you're going to have- your options at the bottom, so I knew exactly where to go. And I did not have any, nothing was confusing (P2)

I think it's easy, and fast, and convenient. (P6)

Talking to Gia was not very different from talking to a real person (7/8); leaders would not have given different answers to a real person (7/8)

It was very easy! It seemed like I was talking to a real person. It was like, you know, you answer it right away, you get an answer. And it's right on the dot, you know, it's relevant [sic]...relevant, I'm sorry. It's relevant and it's accurate. And I mean, it's really easy to use. I was very surprised. (P7)

Because [Gia] were [sic] like um, like uh... let's say talking to a person, a real person because this was straight to the point. Very, the questions were very clear, you know? I like it. (P8)

Gia being offered in Spanish is beneficial (7/8)

I think it's a good thing that it was offered in Spanish. You know, I think it's a great thing because the link will go back to the language barrier. That's an obstacle that is kind of like, okay, that's not an obstacle here. You can still do it. If you don't speak English. (P7)

And it can be done in Spanish, actually, for the client so they don't have to pay more money for an interpreter. I mean- it's good for me that I have that job, okay? But, but it, I mean, realistically, you know, it's gonna be good for, for clinics if they actually have the clients to, to pre check in, you know? Get from it all the information, so. I thought it was awesome. I love it. (P3)

Oh, when it's medical, even when I have a little bit of training, medical because I was an interpreter and I work in a health department and I'm a public health educator. For me if I had to pick and choose between when it's anything related to medical, if I had to pick and choose, I will pick the Spanish because it's my first language and I feel more comfortable reading it. And second is because if we're going to offer this, I'm here to represent the Latino community. (P4)

Gia is time saving (6/8), can be done on an individual's schedule rather than a clinic's (6/8), and can be done at one's own pace (5/8)

If everybody was was [sic] able to provide that kind of basic information, like a foundation for your medical chart, before the doctor's office, the doctor's office visit would be shorter and to the point...Plus, at home, you have the benefit of like, "oh, let me see. Let me call my mom". And then you call your mom like, "Mom?". You gather that information. You have time to gather that information beforehand. (P7)

Yeah, like time. Like, I have four kids. And for me, it was the time, was perfect. (P6)

Because I can do it in my own time. I can, I sit down yesterday afternoon and I knew that I going to do that. And I got ready myself. You know, when you, all the time when you, I mean, maybe not everybody but for me when you, when you go to the doctor's office and because that doctor have to, sometime have other patient [sic] waiting you feel like they're rushing, and you forget things and you say "shoot, I should have saved it" (P4)

Gia was easy to understand (5/8)

Well, because everything was like, every question was clear, I guess. Yeah. Like I said, when they do the genetics stuff, I like that, it was so clear. (P6)

Well, um, for some reason I forgot to use the Spanish version so I didn't try in Spanish, but, but as far as I did it in English, it was the word.... how do you say that? Is the literacy level was appropriate. (P1)

The questions were short, right to the point. I really like that you did not give a whole paragraph of, you know, long extensive, I don't like those either, but they were very simple, very easy to understand. (P2)

Gia was a safe, private experience (4/8)

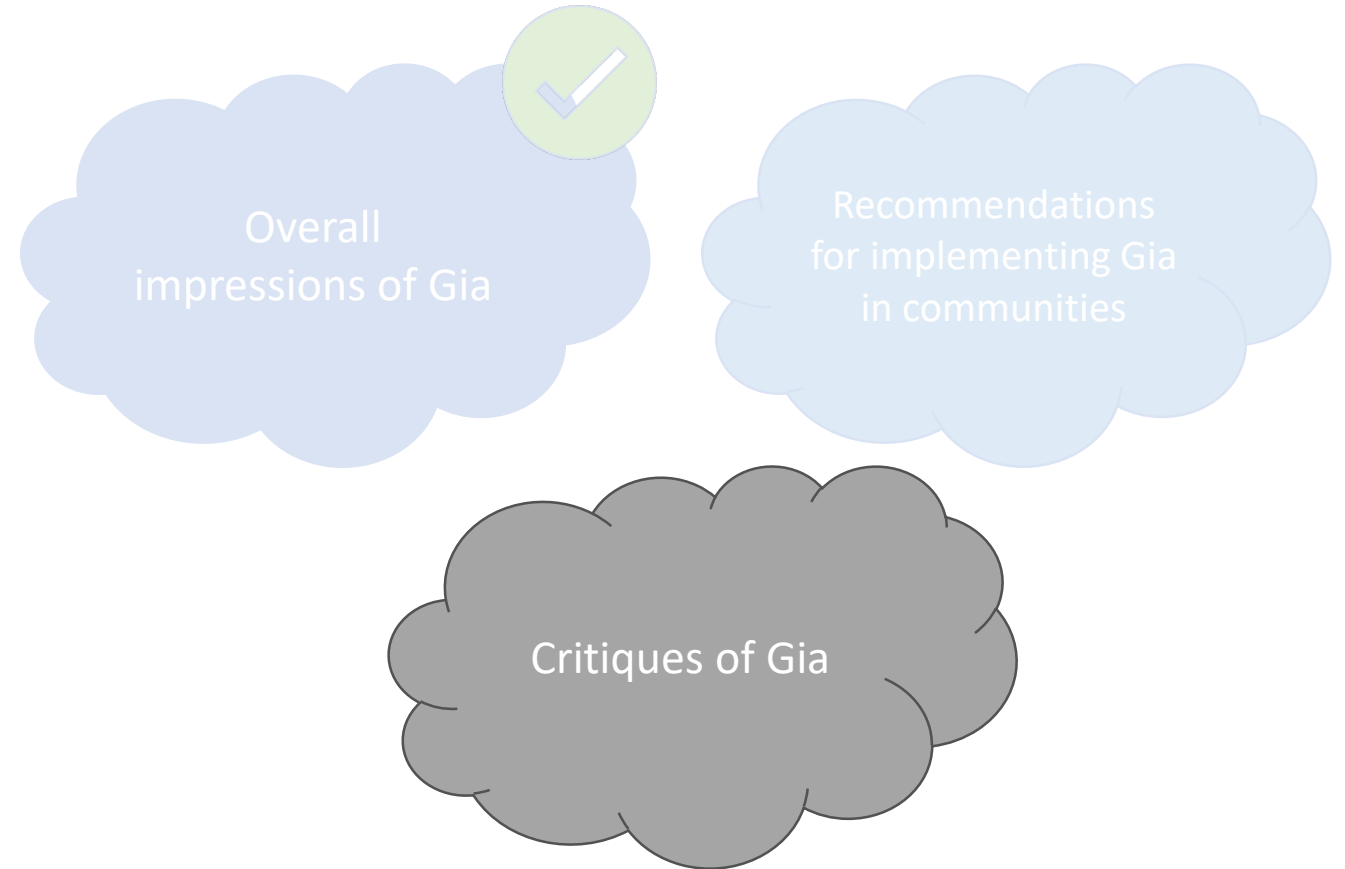
And actually, I was asking this previously, right, if the chatbot is HIPAA compliant, and I totally for me the experience was very nice, very safe. HIPAA compliance [sic], because I never say, or posted my name or my, my personal information. So, just at the end, when I believe when you try to refer the individual to a genetic counselor is where you get that information. But, but, even though I believe I've responded to one of the- oh! When you say you have an option, that, well, the chatbox [sic] have an option, that if you want to leave a comment. And even with that you have a note there stating that, "Okay, please don't disclose personal information". So that's amazing. So that remind us that we cannot disclose that information is very important. (P1)

I was sure that I was answering the question the best of my abilities so that was very helpful and make me comfortable and also I'm at home where I can feel safe and comfortable and secure. (P4)

Themes: Interview 2



Themes: Interview 2



Gia's medical and genetics terminology may be too advanced for some users (4/8)

And something that I think there's- like we talk, people don't know much about the type of cancer. You- they have a list of, a list of several like a pancreatic cancer, liver cancer. And I think for many, probably for the majority I don't want to say for everybody, but for a group of people that are not familiar with that terminology I don't know if putting a little explanation next to it will be helpful, I cannot tell, but I know by when I talk to people about diabetes, and I explain about any kind of, you know, the liver, how the diabetes can damage the rest of the body, the liver, the pancreas and everything else, people kind of look at me like I'm not sure they're understanding because again, they're not, they know we have those organs but they don't know where exactly are located. Everything is the stomach. (P4)

The A D N, the ADN, I want to say, how do you say in Span, in English? ADN? Oh... DNA! DNA! Yes, it was a little bit confusing. (P5)

Some of the definition is a little bit, the level of the definition is too high. So they, many individuals, even though you have the definition there - so you have the definition if you go over and move, move, the cursor to the word, and I know you can expand the definition - but is too high, is just, like, for many individuals... (P1)

More colors/visuals could increase appeal with Hispanic communities (3/8)

Because it says here, “you may already know that the human body is made up of millions of cells and within those cells are the genes”, okay, and I was thinking okay, you're talking about cells. Those are the genes. So you are going boom boom boom boom like that. Yeah, just a little bit of color would make it. And even if the colors match the words, genes, DNA, I mean just to- You could separate right away with colors, which one is which. (P2)

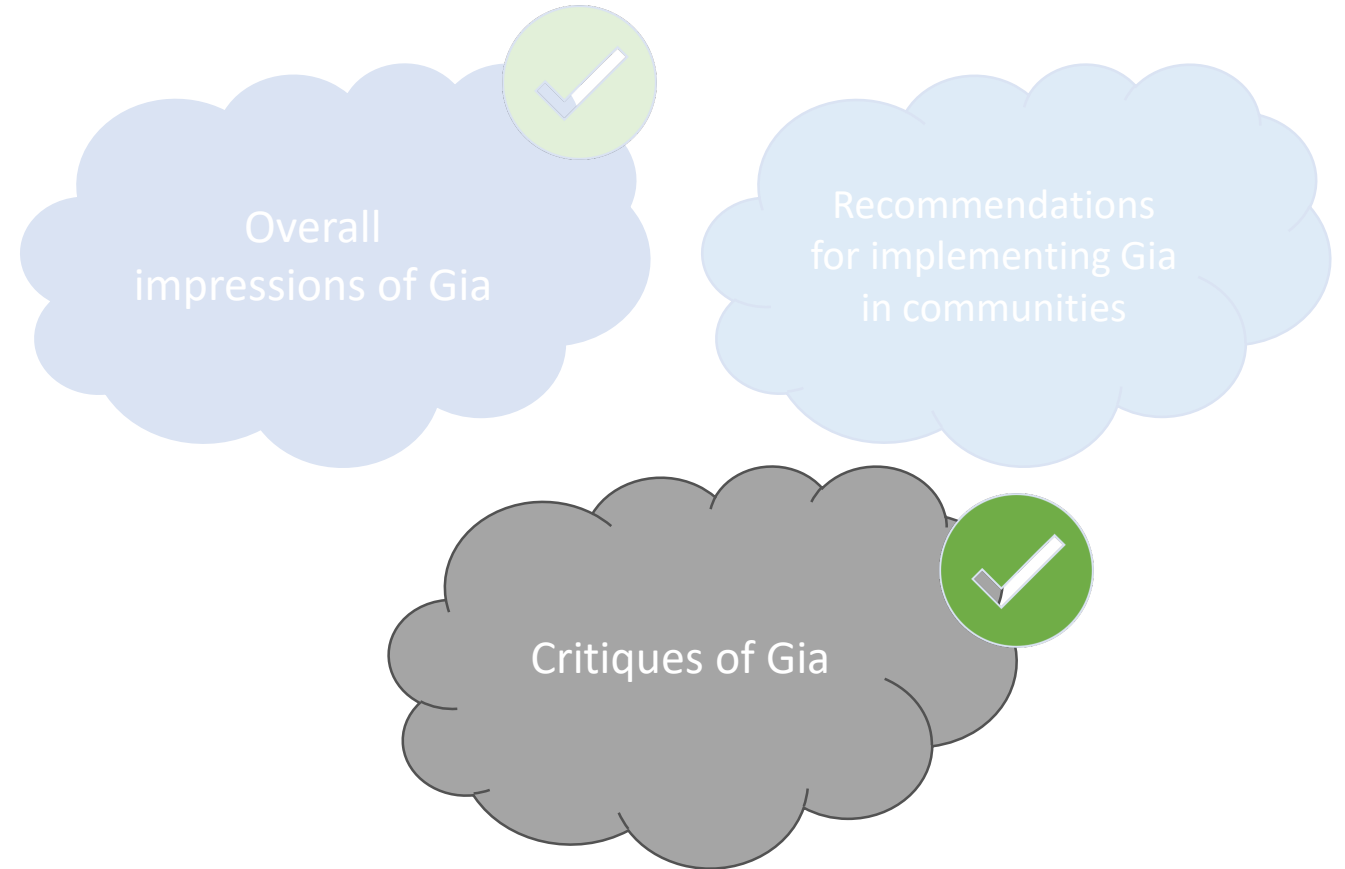
I wish wish you can have more pictures, right or more happy faces that you know, like, I don't know, or I mean, I really like the emojis. I think we're getting more familiar with, with those images or those I don't know how to call it pictures, emojis to better assess their, you know, their whatever you are assess, you know, like the, like if you're satisfied or not, you know, it's easier for those families that don't have a lot of reading skills. (P5)

Typo in Spanish (1/8), no uninsured option (1/8)

And, one of the questions that in Spanish that asked about your height, the translation in Spanish says, "What is your age?" and instead to say, "what is your height?" or estatura. And I just like I went back and I read it, say maybe I misread it, but no, it's need to be correct. My suggestion is to be corrected to the right terminology. (P4)

Okay, so at the end, so... they, there is an option that "okay, you can be referred to a genetic counselor, please provide your information", and you have the option to skip those options as well. But there is an option in each space, "please provide your insurance". And, but during the chatbox, the chatbox [sic]...they, Gia, inform that, because is going to be like \$250 for the lab test for people, for uninsured people, or uninsured individuals. So, but at the end, you don't have the option to say, "Okay, I don't have insurance", you have the option to, you have the drop off asking which type of insurance. So you cannot, you will, there is no way you will get the patients or the individuals' information, the uninsured individual's information, if you don't change that option... So what I'm saying is that, yeah, you should...the Gia chatbox [sic] should have an option for uninsured individuals, mostly for the Hispanic/Latino community, you know, many people are immigrants and they cannot afford to pay an [sic] insurance. (P1)

Themes: Interview 2



Themes: Interview 2



A trusted individual to walk families through Gia could increase uptake amongst people less comfortable with technology (6/8)

Depending on the level, I think many families will take it in a good way. Many, many families will take it as a big challenge. Because it's working with electronics, working with a media, working with, you know, they just don't know. So they're gonna rely on someone else to help them out. (P3)

Some of them, like I told you before, when immigrants came here in the first place, they don't trust technology that well, but I was talking about, depending what generation the technology we're using [sic], because you got to do like a meeting before you use that, like you're talking with a real person and explain them that it's a safe website and you know, the information they put in there is not sharing with nobody, you know. Like that. (P6)

Adding more of a personal touch to Gia implementation could be valuable for Hispanic communities (4/8)

I know machines are so... as things, they go with whatever question they go, but sometimes, you know, if it's a human, like, "Hi, how are you? How are you today? How are you doing?" and you know, sometimes we miss that, especially now with the COVID-19 everything, like everybody is insulated from each other. And sometimes we miss that, you know. Maybe if they use that, first, if first like you call me, then say "hi, how are you? You know, you're going to do this online and my name is [interviewer]". (P6)

Gia could be helpful for cancer screening in regional Hispanic communities

[Gia's] **easy to get**, it's **easy to navigate**, and **it would really make them aware of how [cancer] could**, it could, it could **actually exist within their families**, and the fact that you explain your immediate family, I mean your family is your, your cousins, your, your- I'm sorry not cou- did you include cousins? Yes, I think it said grandparents, siblings, parents...and many times families don't think that far. You just think your children and your parents and that's it. I'm trying to find that, that, that question. But the fact that it's- Oh, here it is. So you said, parents, brothers, sisters, half-siblings! Didn't even think about that. Children, grandparents, aunts, uncles, nieces, nephews, and cousins, that, that is, **I mean, a number, a ramification of your family that you many times don't even think about. So this is really good, that, that information.** And **it goes fast**, so I think **families spend so much time in their phones nowadays, it's right there available for them.** And if they have further information it's something workers to- you know, a red flag would, would show up, I mean, **they would be now more willing to check with a doctor**... many times like I was sharing with you at the beginning, they don't go to a doctor because of lack of transportation, because of language issues, because of insurance issues... This is- **I see it like a good way to get a screening, to see if I really need to go to see a doctor and follow up on this.** So, I think, yeah, I will definitely share it with families and explain to them that it's confidential, and it does tell you that at the very beginning. So that's very good that you do that. (P2)

Summary of Results

Study Aim 3: Evaluate acceptability of Gia amongst regional Hispanic/Latinx community leaders

- All community leaders **would recommend Gia** to community members (8/8)
- All community leaders **liked Gia** (8/8), most described Gia as **easy to use** (7/8)
- Talking to Gia was **not very different from talking to a real person** (7/8); leaders would not have given different answers to a real person (7/8)
- Gia being offered in **Spanish is beneficial** (7/8)
- Gia is **time saving** (6/8), can be done on **an individual's schedule** rather than a clinic's (6/8), and can be done **at one's own pace** (5/8)
- Gia was **easy to understand** (5/8)
- Gia was a **safe, private** experience (4/8)

Chatbots like Gia can address top barriers to care in regional Hispanic communities

- **Documentation status** -> not a factor in Gia eligibility, PAP eligibility
- **Language barriers** -> available in English, Spanish
- **Income and insurance** -> Gia is free, covers pre-test counseling, can be paired with PAP for free testing
- **Competing priorities** -> Gia can be done at any time and can save time
- **Increased need for education about cancer** -> Gia provides bilingual cancer genetics education
- **Interested in learning more about their cancer risks (8/8), with caveats (6/8)** -> Gia informs on family history-based risk, and per community leaders could be introduced by them to build trust
- **Increased need for literacy and baseline education** -> family or community leaders can help with Gia use*
- **Awareness of existing cancer services and the U.S. healthcare system** -> addresses gap in awareness about cancer genetic counseling and testing

Chatbots like Gia incorporate some health education approaches used by regional Hispanic community leaders

- **Trust** is a motivator in health-seeking behavior -> community leaders anticipate high uptake of Gia with introduction by trusted individual
- **One-on-one education step-by-step** through a process -> Gia is self-paced and allows user to clarify any uncertainties, delivers education step-by-step
- **A personal touch** -> Gia is not very different from talking to a real person, can be personalized
- Providing education **in the target audiences' communities** -> Gia can be done at home or in a community setting
- **Simple language** is important -> most community leaders found Gia easy to understand
- Resources and education should incorporate **different languages** -> Gia is bilingual
- Resources should incorporate **colors and visuals** -> Gia has a familiar visual format, pictures and videos

Discussion

Practice Implications

- Gia could help genetic counselors reach underserved populations in a culturally-friendly, resource-friendly manner
 - Emphasize free, private, fast, bilingual, WhatsApp-like, schedule-friendly
- Offering, educating on documentation-friendly cancer genetic testing (e.g. Invitae PAP)
 - Having free screening resources ready to provide
 - Having free or low-cost treatment options (Medicaid?) ready to provide
 - Cost transparency about post-test genetic counseling
- Emphasizing the family rather than the individual's health re: cancer genetic testing



Conclusions

- This is the first study to assess acceptability of an AI chatbot for cancer genetic screening in Hispanic populations in Oklahoma and Nebraska
 - Gia could help overcome some barriers to care in our region, increasing genetic counseling and testing uptake, and reducing cancer morbidity/mortality
- This is the first study to evaluate barriers to cancer genetics care for Hispanic populations in Oklahoma and Nebraska
 - Can inform outreach, education, cancer care access initiatives regionally



Future directions

- Evaluate acceptability of Gia amongst Hispanic community members
 - Differences in educational attainment inform preferred health information source in Hispanic adults (Iacobelli et al. 2021)
 - Poss lower literacy – lower acceptability of Gia?
- Education and outreach about cancer prevention, Gia to local Hispanic communities
- Larger sample – Hispanic communities highly heterogenous

Questions?

Please also feel free to email
me at
sophiagokc@gmail.com!

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Q+A slides

APPENDICES

APPENDIX A: INTERVIEW QUESTIONS

These are an example of the questions we will ask participants.

Again, I would like to remind you not to state your name or the name of any other persons. Thank you for agreeing to collaborate with us today.

Demographic info

1. What is your age?
2. What is your gender?
3. What is your preferred language?
4. What is the highest level of education you have completed?
5. What is your family's country of origin?
6. Do you ever visit your family's country of origin?
 - If so, how often do you visit?
7. What is your household's estimated yearly income?
 - Below 20,000? 20,000-40,000? 40,000-60,000? Above 60,000?
8. What insurance plan do you currently have?

For community leaders (focus group):

- About outreach, education, and access to healthcare...
 - Have you noticed any reasons why people or families may not be able or willing to access health services?
 - If yes/no response: tell me more about that.
 - In what ways are the community's needs being met for cancer screenings and/or cancer treatment?

- In what ways are the community's needs not being met for cancer screenings and/or cancer treatment?
- Tell me about how cancer is talked about in your family or your community.
 - Who do individuals talk to about it?
 - Who do they not talk to about it?
 - If cancer is not talked about, can you tell me more about that?
- From a family health perspective, do you believe families would be interested in learning more about their cancer risks?
 - If yes/no response: tell me more about that.
- What outreach or education methods have you used to engage families in the community?
- Have you used medical portals through health systems before?
 - In what ways have you used medical portals?
- Are you familiar with chatbots?
- Have you used a chatbot before?
 - Can you tell me more about that? What was your experience like?
- What information about Gia and the program we are considering implementing do you feel is most useful for community members to know?
 - In what ways can we design our educational materials to be culturally appropriate and easy to understand for Hispanic families?
- What else would you like to know about Gia before you try Gia?
- What else would you like to know about Gia before you recommend Gia to others in your community?

- I've asked the questions that I know to ask from my perspective. From your experiences, are there cultural or other reasons that would prevent someone from your community getting the care they need?
- About Gia (after participants have interacted with Gia)
 - What is your overall impression of Gia?
 - How is communicating or interacting with Gia different from communicating with a real person?
 - Do you feel that you would have given different answers or responded differently if there was an actual person on the other side of the conversation?
 - What parts of interacting with Gia were confusing?
 - What are your thoughts about using Gia to collect family history at home (or wherever you feel comfortable) instead of going to a clinic to give a family history and learn about cancer?
 - How do you feel about writing or texting with Gia in your language of choice?
 - Thinking about your family members, friends, and community, what do you think their response might be to Gia?
 - Is Gia a tool you would offer to individuals?
 - If yes/no response: can you tell me more about that?
- Finally, is there anything that may have come to you during this interview that you would like to share on any of these topics?

For individuals who decide not to start or complete Gia:

- What were some reasons you decided not to use (or complete) Gia?

Question Path Development

- Informed by literature review
 - Oklahoma and Nebraska-based Hispanic/Latinx populations accessing pediatric genetics services (Hallford et al. 2020)
 - Barriers to cancer genetic counseling for Hispanic/Latinx communities in urban settings (Rajpal et al. 2017; Sussner et al. 2015; Sussner et al. 2013)
 - Study on Gia for delivery of genomic results in a predominantly white, Mid-Atlantic cohort (Schmidlen et al. 2019)
- Demographic questions → education/access to cancer care questions → pre-chatbot technology questions → post-chatbot questions



Limitations

- Recruitment stopped due to pragmatic concerns rather than sample saturation
 - Small sample size
- Exclusively female sample may limit barriers uncovered, opinions on Gia
 - Loss of provider role a deterrent to cancer care for some Hispanic/Latinx men (Sussner et al. 2015)
 - Hispanic adults of different genders place different levels of trust in different sources of cancer health information (Martinez-Tyson et al. 2017; Camacho-Rivera et al. 2020)
- No coders who identified as Hispanic/Latinx