NORTON & ELAINE SARNOFF CENTER FOR JEWISH GENETICS

COMMUNITY **NEEDS** ASSESSMENT

2018

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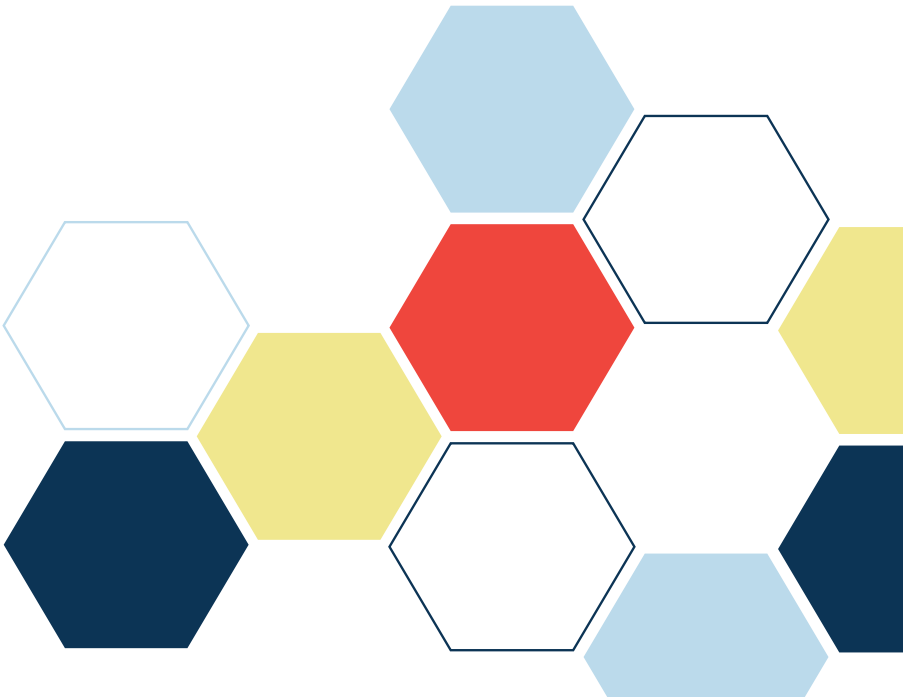

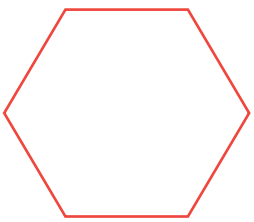

EXECUTIVE **SUMMARY**

People of Jewish ancestry face elevated risks for certain genetic disorders and hereditary cancers. The Norton & Elaine Sarnoff Center for Jewish Genetics conducted a year-long community needs assessment to learn what at-risk individuals in Chicagoland know about Jewish genetic health, how they learn about it, and where there are gaps in knowledge or barriers to raising awareness.

What we did and why

We used surveys, interviews and focus groups to learn from 223 communal professionals and laypeople. We sampled for diversity in age, life stage, gender, denomination, geography, and other demographic factors to characterize overall engagement with Jewish genetic health in at-risk communities as well as differences between subgroups.

Findings

Knowledge of Jewish genetic health is low.

People might be aware of Jewish genetic disorders and hereditary cancers, but they don't know what these concerns mean for their own health or for their family's health. Many misconceptions about Jewish genetic health dissuade people from seeking out more information and screening. These issues may also cause psychological distress—people often think of them as "scary" and prefer to avoid thinking about them.

Life experiences influence awareness of Jewish genetic health topics.

People find Jewish genetic health information most salient when they can see its impact on their families and social networks. Information about Jewish genetic health diffuses in secular and Jewish educational settings, through the media, and through personal connections to friends, family, and healthcare providers. Some demographic factors also influence awareness: men, less educated people, and people who didn't grow up in a Jewish community all might be less likely to have awareness of Jewish genetic health issues.

Multiple types of touchpoints are necessary to reach people across the lifespan.

Effective strategies for education on Jewish genetic health include creating a general culture of familiarity around recessive disorders and hereditary cancers, while at the same time specifically targeting people when they will find information most relevant and actionable (e.g., during family planning, after a family cancer diagnosis). The most successful education models target community members directly, but also extend to professionals who can share information with the community members they serve. Community education has the broadest reach when it accounts for different types of access, reflects varied learning styles, and leverages peer and family networks.

Recommendations

This needs assessment informs the launch of our Genetic Health Education Initiative, a three-year project designed to raise awareness about Jewish genetic health topics in both Jewish and secular settings. Based on these findings, we have recommendations in four areas: 1) focus **messaging** on empowerment and actionable information about Jewish genetic health, 2) diversify **outreach** to support underserved at-risk populations, 3) strengthen & develop small-scale, activity-based **programming** for a variety of audiences, and 4) plan **assessment** of professional education needs and feasibility of peer education programs.

JEWS AND **GENETIC HEALTH**

The Norton & Elaine Sarnoff Center for Jewish Genetics was founded in 1999 as the Chicago Center for Jewish Genetic Disorders, with a mission to educate the Chicago Jewish community about genetic concerns. Due to historical factors, a number of genetic diseases occur more frequently in the Jewish population.[1] This means that individuals with even just some Jewish ancestry face elevated risks for certain genetic conditions. The Sarnoff Center focuses on two main types of genetic health concerns: recessive genetic disorders and hereditary cancers.

Recessive disorders

One in four people of Jewish ancestry is a **carrier** for a recessive genetic disorder that is more common in the Jewish population. Carriers generally have no symptoms, but two carriers of the same disorder have a 25% chance of conceiving an affected child with each pregnancy, and a 50% chance of conceiving a child who also carries the disorder. Figure 1 illustrates recessive inheritance patterns. Most of these disorders are incurable and lead to a shortened lifespan, and some are fatal in childhood.

Tay-Sachs disease was the first widely recognized genetic disorder in the Jewish community, and generations of families were devastated by children lost in early childhood due to this fatal degenerative illness. Although Bernard Sachs first described the prevalence of the disease among Ashkenazi Jews in 1887, it would not be

Note: *Terms that appear in* ***bold*** *throughout the text are linked to definitions in the Glossary (pages 34-35).*

until more than eighty years later that researchers understood that the disease was caused by a deficiency in an enzyme, Hexosaminidase-A (Hex-A), and that carriers too showed reduced enzyme activity. This knowledge led to **community screening programs** in the Jewish community beginning in 1971, and a subsequent drop in Tay-Sachs rates in the community below that of the general population.

Jewish communal leaders encouraged all reproductive-aged people of Jewish ancestry to get screened, and screening programs quickly expanded to include additional recessive disorders more common among persons of Jewish descent. Couples who were both found to be carriers of the same conditions had the option to engage in alternative family planning strategies or prenatal testing—genetic testing during pregnancy—to avoid having children with the fatal disease.

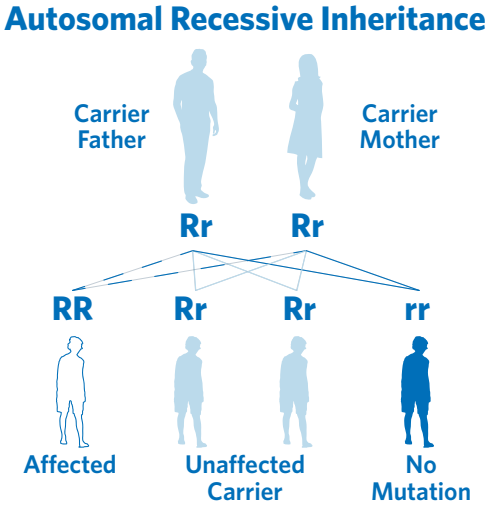

Figure 1: If both parents are carriers of a recessive disorder, they have a 25% chance of conceiving a child affected by the disorder with each pregnancy.

Since that time, technological advances have dramatically shifted the landscape of carrier screening. Now, screening is available for dozens of Jewish genetic disorders, such as **cystic fibrosis** and **familial dysautonomia,** as well as **X-linked disorders** and recessive conditions more common in individuals of other backgrounds. As the number of conditions on screening panels has multiplied, so has the complexity of sharing information about screening. Reproductive technologies make it possible for carrier couples to have healthy children through their choice of methods.

Hereditary cancers

Not all genetic disorders that are more common in Jewish people are recessive. In the mid-1990s, scientists identified mutations in two genes seen in a large number of families with a significant history of breast and ovarian cancer.[2] They named the genes ***BRCA1*** and ***BRCA2*** for BReast CAncer. Mutations in the *BRCA1* and *BRCA2* genes can affect men and women, and also increase risk for pancreatic cancer, prostate cancer, male breast cancer and melanoma. BRCA mutations are ten times more common in people of Jewish ancestry than in the general population: One in 40 people of Jewish ancestry has a mutation, compared to about one in 400 in the overall population.[3]

In the past twenty years, scientists have made great strides in understanding BRCA-related cancers, and other genes linked to **hereditary cancer syndromes.** Persons who test positive for a cancer-causing mutation now have several evidence-based strategies for reducing their risk that range from earlier screenings to risk-reducing surgeries.

Community awareness

As scientific awareness of Jewish genetic disorders has deepened, the landscape of risks and options has become more complex for individuals to navigate. Many people do not feel that there is anything they can do about genetic health, and so they may choose not to engage in learning about it at all. People of Jewish ancestry—especially those who have just one Jewish parent or grandparent—may not think that their ancestry is relevant health information, which may lead them to fall through the cracks in the medical system. They may never receive carrier screening, or they may delay screening until after conception, when they have fewer options for family planning. They also may not receive appropriate **cancer risk assessment.**

Laypeople rely on their medical providers to inform them of genetic health risks, but even medical professionals may be ill-equipped to identify their at-risk patients and to have conversations about genetic risk with them. Most healthcare providers receive little training in genetics, so they may not know how to identify a person at risk, or know what screening recommendations apply to a patient with a given risk profile. Additionally, healthcare providers often have limited time to discuss a range of health concerns with their patients. Because Jewish individuals represent only 2% of the U.S. population,[4] healthcare providers may not inquire about Jewish ancestry during preconception or cancer risk consultations.

BRCA mutations are ten times more common in people of Jewish ancestry.

At the same time, increasing numbers of companies offer genetic testing through a **direct-to-consumer (DTC) model**—without appropriate genetic counseling or physician follow-up. Such companies have offered limited carrier screening results for years. Consumers can also receive information about their risk for certain BRCA mutations commercially, without an order from a medical professional. Individuals often lack the tools they need to understand the information they receive about their genetic risks through such tests, or to understand the limitations of such testing.

Individuals and communities lack needed support in understanding, assessing, and managing genetic health risks. Professional education and building community-wide awareness of Jewish genetic health concerns are both critical to addressing these challenges. The Sarnoff Center works to meet both of these needs through educating clergy, medical professionals, and the community.

In summer 2017, the Sarnoff Center launched its Genetic Health Education Initiative, a three-year process to increase understanding of Jewish genetic health among at-risk communities. To best serve the community, we need to understand how Jewish and interfaith families in Illinois engage with Jewish genetics topics. Therefore, step one of the Genetic Health Education Initiative was the Sarnoff Center's first large-scale project to characterize awareness of Jewish genetic health in Illinois via a mixed-methods **community needs assessment** conducted over 2017 and 2018.

Our goals for the needs assessment were:

- Find out what people know and don't know about Jewish genetic conditions
- Identify where people are learning about Jewish genetics
- Explore what makes some people feel they are more at risk for genetic disorders than others
- Explore what prevents people from getting education and genetic screening

With that information, we planned to:

- Identify how we can help people learn about Jewish genetic health
- Develop a plan to fill gaps in understanding with education and programming

Our methods

We conducted interviews and **focus groups** and, in conjunction, collected surveys in person and online. We spoke with three categories of **informants:** 1) foundational informants: Jewish professionals who served as nodes for contacting other professionals, 2) communal professionals, 3) laypeople. First, we conducted nine initial unstructured interviews with Jewish professionals whose primary role is supporting other professionals.

These interviews helped us build a list of organizations and contacts for sampling purposes. Since these interviews focused on mapping Jewish communal organizations and not Jewish genetic health, they did not become part of the final dataset.

We used the list of contacts and organizations as a starting point for reaching out to Jewish communal professionals and laypeople. We conducted **semi-structured interviews** and focus groups with these two types of informants. We also surveyed lay informants. We proceeded with community buy-in at each step and used **snowball sampling** to identify influential community leaders and hard-to-reach demographics (e.g. people with Jewish ancestry who do not identify as Jewish).

We used **SPSS** to analyze the survey data and coded the interview and focus group data to look for emergent themes. We used three quantitative outcome measures: 1) knowing someone who has gone through carrier screening, 2) knowledge of recessive genetic disorders, and 3) knowledge of hereditary cancers. We assigned knowledge level based on the proportion of survey questions answered correctly about each topic.

We learned how individuals as well as Jewish institutions address these topics.

By including both laypeople and communal professionals, we learned how individuals as well as Jewish institutions address these topics. We purposefully sampled for diversity in geography, gender, age, life stage, Jewish affiliation, and observance to get a broader picture of community needs.

Using mixed methods—quantitative and qualitative—was ideal to assess comprehension of Jewish genetic health topics at a community level and also learn how people apply information about genetic health in their day-to-day lives.

Participants

Communal professionals

After gathering contacts from foundational interviews, we spoke with 35 community leaders in semi-structured interviews and focus groups. They included rabbis, engagement professionals, and educators. We heard from professionals based in Orthodox, Conservative, Reform, Renewal and nondenominational settings. They serve individuals across the lifespan, including: teens, college students, young adults, young families, midlife adults, and older adults in Chicago and the surrounding suburbs.

Individuals/Lay participants

One hundred eighty-eight individuals completed a survey about their beliefs and perceptions of Jewish genetic health. One hundred nine of those individuals also shared their experiences in an interview or focus group. We facilitated focus groups at a youth group event, university Hillels, a young adult (20s and 30s) program, Jewish lay leadership meetings, and synagogues to include individuals across the lifespan. We used snowball sampling to reach individuals who are less likely to attend a Jewish community event. Lay participants range in age from 16 to 86, with a median age of 43. Two-thirds of participants are women and 30% are men.[5] They live in 65 different zip codes throughout Chicagoland and Urbana-Champaign. Almost all have Jewish ancestry. Those who do not (n=4) have Jewish spouses or partners. Twenty-two percent of coupled participants are in an interfaith relationship. Figure 2 illustrates the sample and data collected.

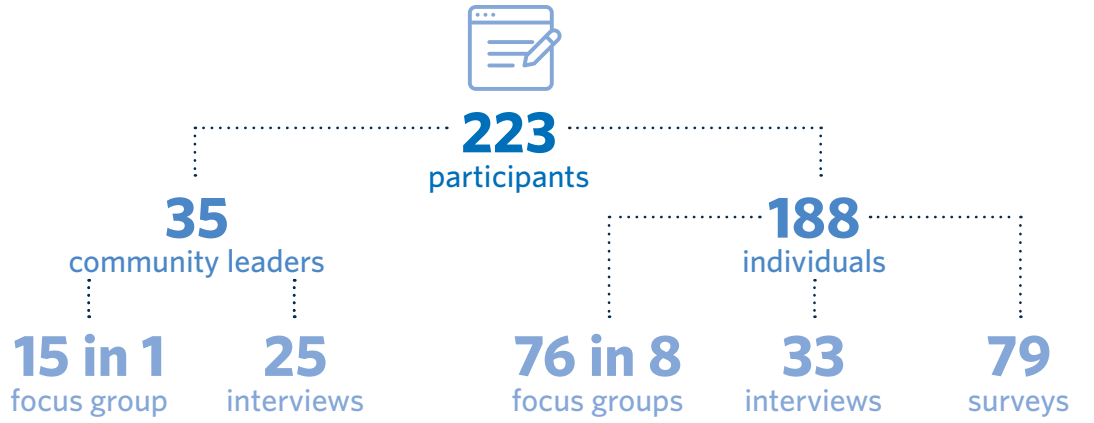

Figure 2: Summary of data collected from each type of participant

Framing

From individual genetic variations to the broader environment, influences on health operate across a variety of levels. Drawing from the **Healthy People 2020** initiative, we frame our discussion in an **ecological and determinants approach to health.**[6] This means that we focus on how different dimensions of influences interact to shape engagement with Jewish genetics. The **health determinants** we will explore are on multiple levels: individual, interpersonal, organizational, and community. We note how those layers independently and interactively shape knowledge of Jewish genetic health. The most effective health education programs take into account multiple layers of influence, so we factor these dimensions into our recommendations. Figure 3 illustrates our framework, a modified version of the Healthy People 2020 Framework.

Figure 3: Ecological and determinants approach to health

FINDINGS

We drew three main conclusions from the data.

1. Knowledge of Jewish genetic health is low
2. Life experiences influence awareness of Jewish genetic health topics
3. Multiple types of touchpoints are necessary to reach people across the lifespan

Finding 1: Knowledge of Jewish genetic health is low

On an individual level, people may be aware of the relevant concepts but are unlikely to understand them well enough to know how to use the information for their own and their family's health. Even most respondents who had heard of Tay-Sachs disease and BRCA mutations were not familiar with the risks, screening recommendations, or methods for prevention and risk-reduction. As an analogy, this is the equivalent of knowing that people get heart disease, but not understanding what factors contribute to developing heart disease, how to determine one's own risk, and how to reduce the likelihood of developing heart disease through behavioral change and medication. Being able to identify a disorder is a first step, but is not particularly useful without functional knowledge about how to reduce one's own risk of being affected.

Needs assessment participants reported low levels of understanding about Jewish genetic health across a range of topics and at-risk populations. An obstetrician-gynecologist practicing in Skokie said, "I do get a lot of patients who are confused and who are completely uneducated in this set of risks." Jewish clergy also perceive that most people don't understand their risk. A rabbi said, "I think that people don't understand the extent of Jewish disease. I think that everybody is aware of Tay-Sachs. Most people are aware of BRCA. I think that once you get past those two things awareness drops off precipitously." In fact, several participants had never heard

of Tay-Sachs or BRCA. Participating in an interview or focus group was their first exposure to the concept of Jewish genetic disorders.

Jewish institutions, such as synagogues and community organizations, do not address genetics and health in their usual programming. In a few cases, organizational leadership shared that they had recently done a program or shared resources on Jewish genetics, but for the most part they felt that it "just doesn't come up" with congregants or constituents. "I think there's a real lack of an educational piece about Jewish genetics," said one Jewish professional. Another said, "There are things we just don't know, and we probably should know, and could do a better job of both education and programming."

Recessive disorders

Most participants had heard of recessive disorders, but only two-thirds of respondents reported knowing someone who had gone through carrier screening, testing that is recommended for every couple that is planning on having a child to determine risk of passing on a recessive disorder. The optimal time for carrier screening is when thinking about getting pregnant because carrier couples have the most options before they conceive. Yet many respondents did not go through carrier screening when they were planning for a family. Most could not name any Jewish genetic recessive disorders beyond Tay-Sachs disease.

Only two-thirds of respondents reported knowing someone who had gone through carrier screening.

BRCA1 and *BRCA2* mutations

Many people did not realize that people of Jewish ancestry are ten times more likely to have a BRCA mutation than the general population. Multiple participants who have a BRCA mutation themselves did not know about this elevated risk. 42% of people surveyed—almost half—didn't know their Jewish heritage can indicate that they have an increased risk for cancer. "I think that the genetic piece, people think about right away in terms of having kids, but I think not as many people are aware of the cancer genes," a rabbi said. A few participants also indicated that they thought BRCA primarily affects women, when in fact men are just as likely to have a *BRCA1* or *BRCA2* mutation as women and can pass it on to sons and daughters just as mothers can.

Family health history

One important component of evaluating risk for hereditary cancers is family health history—a record of family members' health conditions, ages at diagnosis, and causes of death. Most participants understood the concept of family health history but did not have a strong grasp of their own because of a lack of information-sharing on an interpersonal level. One healthcare professional said, "I used to see patients all the time and ask them about their family history, and almost nobody had it really down." As a result, people might regularly miss indicators of hereditary cancer in their family, such as multiple relatives with the same kind of cancer.

Genetic testing

Participants were unsure what protections exist to keep their genetic information secure, and many said this would deter them from seeking out genetic screening. One college student recounted that her mother had discouraged her from getting carrier screening, telling her, "there are all kinds of privacy issues." There are laws in place to maintain the security of genetic information, but many participants were unfamiliar with these

laws.[7] This policy landscape and the lack of accurate communication around these laws impacts awareness of Jewish genetic health.

Most participants were familiar with genetic testing that is available without a medical order, known as direct-to-consumer testing, but many had questions about how that kind of testing differs from genetic testing through a healthcare provider. At an organizational and community level, messaging around genetic testing options can be confusing. Especially now that some direct-to-consumer genetic testing companies offer limited carrier screening and testing for BRCA mutations, understanding differences between types of genetic testing is necessary to make an informed decision about whether, and how, to undergo genetic screening.

People also often confused testing for BRCA mutations, called "**cancer genetic testing,**" with carrier screening—even though they are rarely offered in conjunction with one another and they serve different purposes.

Misconceptions

We found several salient myths about Jewish genetic disorders that can create barriers to people seeking more information at the appropriate times in their lives. Each concept is illustrated in the words of a participant.

"People think that, 'because I'm not 100% Jewish, I don't need testing.'"

People who have only some Jewish ancestry often feel that they and their families are unlikely to be affected by Jewish genetic disorders. They feel "buffered," in the words of one respondent, by their non-Jewish genetics. This extends to people in interfaith relationships—their intuition is that, even if they are at risk, their partner is very unlikely to be a carrier of Jewish genetic recessive disorders. One physician described how this applies to her interfaith patients, saying, "A lot of them that are intermarrying think that it doesn't apply to them. They'll say, 'Oh, my husband's not Jewish, my fiancée's not Jewish.' I'm like, 'It doesn't matter.'" One participant said, "They might just not think it's relevant." In these cases, individual understanding interacts with interpersonal factors to shape screening decisions. Many participants said they would seek out carrier screening if they married a Jewish partner, but not if they had children with a non-Jewish partner. Anyone can be a carrier for any disorder, so the **American College of Obstetricians and Gynecologists** (ACOG) recommendations encourage couples with even a little Jewish ancestry to get carrier screening. Yet one out of five of participants didn't know that interfaith couples should go through carrier screening.[8]

In fact men are just as likely to have a *BRCA1* or *BRCA2* mutation as women.

"The idea of carrying a disorder and not actually having it is confusing."

The mechanics of recessive disorders can be challenging to grasp. What does it mean that I don't have a disorder, but I could pass one on to my child? People struggle to wrap their heads around how these risks might apply to them. Many respondents said they weren't concerned because they didn't have a family history of recessive disorders, yet 80% of recessive disorders arise in families with no history of them.[9] Most survey respondents (90%) correctly indicated that people with no family history still may need genetic screening, but many did not apply that knowledge to their own circumstances. Even one participant who was exceptionally well-versed on the topic because he had learned about recessive disorders in Jewish and secular settings said

that he had not sought out carrier screening because, he said, he and his wife didn't have a family history of any recessive conditions.

"Could you do anything if you found out you or your partner had it? Could you do anything? Or is it just like, 'Don't have a kid'?"

Many participants did not understand the risks associated with being a **carrier couple** and the technologies available to mitigate those risks. Participants feared that if they went through carrier screening, they would find out that they were unable to have a healthy child with their partner. One Jewish professional explained how this misconception dissuades people from seeking out carrier screening:

> If people knew that there [were] remedies even if you're a carrier, they would be a lot less reticent to find out this information. I think a lot of people are like, "I don't want to know, because what am I going to do if I find out and then I can't have kids." And that's not true, so I think the education piece should be not only, 'let's learn about this,' but 'it benefits you to learn about this.'

Thirty-nine percent of respondents did not know that if two people both carry the same recessive condition, there are actions they can take to have a healthy child. One participant, echoing the sentiments of many others, said, "I didn't even know that if you're two carriers you can do something to stop it." A medical provider said that many couples come to her with that concern. "People want to know that there's hope. So with any medical testing, people don't want to just do this and get a terrible answer. So I'm like, 'If, G-d forbid, you're both carriers for the same thing, you can still have a biological child.'"[10] In addition to reproductive options, in some cases early intervention and treatment can effectively manage Jewish genetic disorders. Less than half of respondents (44%) knew that some Jewish genetic disorders are treatable.[11] At an individual level, people are not aware of their options, and at an organizational level—in Jewish and healthcare spaces—the messaging about options for carrier couples could be clearer.

"I think a lot of people hear BRCA and hear positive and think that they are going to get cancer and it's almost like, 'I'm going to die.'"

As with carrier screening, people sometimes felt disinclined to seek out genetic counseling and cancer genetic testing because they didn't feel that the information would be actionable. One woman, who had a family history that indicated possible risk of hereditary cancer, shared her thought process: "Say I did the BRCA testing and I had it. What can I do with that? What are my options? Besides like Angelina Jolie, getting a double mastectomy. I think that's where I struggle—okay, I knew there was testing, but what is that doing for you besides making you worry? Is there something you can do with that information? Because if there's not, I wouldn't do the testing."[12] Participants who had not undergone testing for BRCA mutations consistently lacked awareness of the range of medical management options available to individuals at risk for hereditary cancers.

Barriers to learning

In part due to these misconceptions, Jewish genetic health can be a challenging subject to discuss. There are also psychological barriers to raising awareness about genetic health that interfere with learning on an individual and interpersonal level. People tend to perceive these topics as unpleasant to discuss for a number of reasons.

"Fear of knowing"

Overwhelmingly, participants referred to Jewish genetic disorders, hereditary cancers, and discussing family health history as "scary" and described themselves as having a fearful relationship with these topics. One woman said, of both BRCA testing and carrier screening, "What if the testing comes out positive? You don't want to know—it's the fear of knowing." People described this fear as arising from a feeling that genetic information is negative and is going to portend death. One man said that this thinking also extends to discussing family health history: "Some people are just uncomfortable talking about their health history because when they think of health, they might think of death and death is scary to some people." This fearfulness of Jewish genetic disorders is a barrier to education and awareness of screening options. People described how they avoid seeking out information about genetic disorders because, according to one participant, "there's scary things you have to do sometimes to manage it."

Fearfulness of Jewish genetic disorders is a barrier to education and awareness of screening options.

"Ignorance is bliss."

In conjunction with their fear of learning unpleasant information, people felt comfortable avoiding learning about Jewish genetic disorders. "People tend to feel like, even with their own health, ignorance is bliss," said one young man. One woman, reflecting on her approach to health information, said, "I actually don't really ever think about cancer risk, mostly because it's not a pleasant topic to think about." People felt the same way about carrier screening. One mother said, "If you just don't know, maybe you'll get a healthy baby and it won't be that big of a deal." Not only are people uncomfortable with learning about Jewish genetic disorders, but they actively resist the information because if they don't know about them, they can pretend the risks do not apply to them.

"These issues are very personal."

Concerns about Jewish genetic disorders often arise at certain junctures in life. These include planning to start a family (a good time for carrier screening) and learning about a cancer diagnosis in the family (a good time for a discussion with a genetic counselor about whether cancer might run in the family, and how to assess that). Both of these moments can be very private and personal—people are unlikely to share widely that they are considering having children, or that they have a family member with cancer. One dad reflected on starting his family: "It's a pretty private thing, which is fine, but a private thing might not always lend itself for people to know about it."

"It feels like there's a stigma attached to it, almost, because people don't talk about it."

Rather than feeling empowered to address their genetic health risks, some people feel ashamed about genetic mutations. This stigma can create a barrier to raising awareness about Jewish genetic health. One Jewish professional reflected on how the stigma associated with genetic disorders can prevent people from seeking information within the community. "Even for someone like me, if a Jewish professional wanted to know about [genetic risks] maybe I would go to someone that wasn't Jewish, because it would be a shame." A few participants compared carrier screening to pregnancy loss and infertility—calling them "taboo." One

participant said, "I think that in general when it comes to illnesses that people don't see, it's harder to have that conversation because it's not as obvious to people. People might not want to feel like they're damaged goods." If people feel ashamed about their Jewish genetics, they might be less likely to share information about Jewish genetic health with their friends and family or to ask for information within their community.

Summary: "I'm first hearing about this right now."

In a handful of interviews and focus groups, participants shared that this project was their first exposure to Jewish genetic health topics. While this was not the experience of the majority, it illustrates that Jewish genetic health literacy is far from ubiquitous. This lack of understanding extends to various areas of genetic health, including recessive disorders, BRCA mutations, family health history, and genetic screening options. Widespread misconceptions and psychosocial barriers dissuade people from seeking out additional information about Jewish genetic health.

Finding 2: Life experiences influence awareness of Jewish genetic health topics

What people do know about Jewish genetic health depends, in large part, on their circumstances. People hear about Jewish genetic health from a variety of sources, but personal experiences can make that passing information stick. Certain life stages and life events are often tied to increased awareness of Jewish genetic health, as are certain demographic categories. These differences illustrate individual-, interpersonal-, organizational-, and community-level determinants of health knowledge. We provide a narrative description of the findings here. See Appendix Figures 1, 2, and 3 for an illustration of quantitative between-group differences.

Personal experiences

"I'm on my toes about it."

People who had personal or family experience with Jewish genetic disorders often had a better understanding of these topics than others. Some people knew that a family member had died of a type of cancer that might have been hereditary. They spoke of having an elevated awareness of cancer risk from an earlier age. One college student said, "My grandmother died of pancreatic cancer. I am on my toes about it. Knowing how common cancer is, too, makes me a little less afraid but it's important to be on your toes if anyone [in your family] has died from cancer." One woman, who had several relatives die from cancer related to **Lynch syndrome** said, "We kind of grew up in this culture of awareness." A few participants knew that BRCA mutations ran in their families, and they themselves had a mutation or had met with a genetic counselor and undergone testing.

In some cases, people recalled that their parents had shared their carrier status and recommended that they get carrier screening. A handful of participants knew someone, or knew of someone, who had been affected by a recessive genetic disorder.

Even when people didn't have direct experience with **single gene disorders** but had conditions with some genetic or hereditary component in their families, they often cited that as an impetus for learning about Jewish genetic disorders. Participants mentioned a range of conditions in their families that led to a heightened awareness of the genetic risks posed by their ethnic or family background, including: congenital heart disease, stroke, Type I diabetes, epilepsy, Crohn's disease, and Parkinson's disease. In general, people who themselves knew someone who had been affected by a genetic disorder or hereditary cancer were more aware of the issues—they hit closer to home.

"Unless it's touched them personally or their families, they probably don't know about it."

Participants who didn't know someone who had been affected by hereditary cancer, recessive genetic disorders, or other genetics-related health issues said, for the most part, that these topics did not feel relevant to them. In focus groups with young adults, the participants consistently said that the idea of getting carrier screening felt abstract to them, because they were not immediately thinking about having children. Participants who had healthy children were equivalently unconcerned about recessive disorders. One participant said, "It's easy to not think about it when it's not an immediate threat to your family."

Another woman made an analogy between carrier screening and vaccination, suggesting that people have trouble conceptualizing the benefits of these technologies when they haven't witnessed the devastating illnesses that can arise without the use of them. As a result, they don't take advantage of lifesaving technologies. "It's like vaccines. People are like, 'We don't know, what's that bad about measles?' I think how bad Tay-Sachs is. I think—really—it kind of closely resembles the vaccine issue, which should not be an issue. The fact that we don't see it, ever."

For people without personal experience of Jewish genetic disorders, or at least some kind of genetic disorders, both hereditary cancers and recessive disorders felt abstract and learning about them was a low priority— as one rabbi summed it up, these issues were "not on their radar."

Age and life events: "It doesn't come up until it does."

Life stage was a critical determinant of how much people understood about recessive genetic disorders and hereditary cancers. Given that people often learn about these topics from personal and family health experiences, it makes sense that certain life experiences or life stages would serve as opportunities for learning about Jewish genetic health.

Young adulthood

People younger than 25 understand less about hereditary cancers than any other age group.

There was general consensus that younger people and single people are less likely to know about recessive genetic disorders and hereditary cancers. Only 44% of people younger than 25 report knowing someone who has gone through carrier screening—compared to 68% of people 25-39 and 87% of people aged 40-54.[13] People younger than 25 understand less about hereditary cancers than any other age group.[14] They understand slightly more about recessive disorders, but still less than people aged 25-39 on average.[15] One 30-year-old woman reflected on why knowledge might be lower among young adults, suggesting that they take less ownership over their health in general. "I think part of it is honestly youth. When I was in college, I did not fill out my own health form—I had my mom do it. When I was in grad school, I dug out the forms from high school and college and filled them out myself. It's just, you're getting older, you're doing more things yourself, and you realize, I can't just go, 'Mommy, will you do this for me,' because I'm not 22." A rabbi agreed. "I'd say older people are probably more aware. Younger people, they have other concerns. I think they're aware when it's brought up to them, like 'Yeah, I remember hearing something about that,' but it's not something they think about a lot."

Marriage & childbearing: "There are just so many factors that go into it, that you don't really learn about until it happens to you or it happens to your friend."

Two experiences pivotal to learning about recessive disorders are marriage and childbearing. These are interpersonal experiences, but they also involve organizational processes and community-wide recognition—they operate on multiple levels to influence knowledge. Approximately three out of four married people and parents knew someone who has gone through carrier screening, but only half of unmarried individuals and those who weren't parents did.[16] People ages 25-39—prime years for carrier screening—knew more about recessive disorders than individuals who were either older or younger.[17] Even though individuals in the 25-39 age cohort were less likely to have personal experience with carrier screening than individuals aged 40-54, their understanding of recessive genetic disorders was more accurate.

Many people first heard about carrier screening as they were planning to start a family. Rabbis sometimes raise the topic in premarital counseling (see Finding 3 for more information on this topic), so couples sometimes heard about carrier screening when planning their wedding—but many did not recall their rabbi mentioning it, or didn't get married by a rabbi.

Many couples that did not seek out carrier screening before pregnancy were encouraged to do so at their first prenatal appointment. Some of these parents and expectant parents said that they had known about carrier screening in advance of pregnancy, but that they hadn't thought to seek it out at that time. Others first heard about it in prenatal care. One dad said, "Like any couple, you decide you want to have kids, so you start trying to have kids. You don't think about all the possible problems. Then when you start to have problems, that's when you get into this stuff."

In some cases, people heard about carrier screening not because of their own family planning, but because of a friend's or sibling's—an interpersonal influence on their knowledge. One woman recalled that she first heard about carrier screening when she and a friend were expecting at the same time. Her friend mentioned in a text that she was nervous about her carrier screening results, and she said, "I don't even know what you're talking about." If her friend hadn't mentioned it, she probably would not have gone through carrier screening.

Cancer: "I know so many women right now who are my age who have breast cancer."

As people age, they, and their peers and family members, are more likely to be directly affected by cancer. Cancer diagnoses can shape knowledge on individual and interpersonal levels. In line with experiences, knowledge of hereditary cancer increases with age: people aged 40-54 and above tend to know more about this topic than younger individuals.[18] One rabbi said, "I feel like I know so many women right now who are my age who have breast cancer, so it's definitely on forty-something mothers' minds." Knowledge of hereditary cancer is also higher among married people than unmarried people, which indicates that expanding family networks might lead to a greater likelihood of knowing someone affected by hereditary cancer.[19]

Overall, awareness of Jewish genetic disorders is influenced by life experiences and life stages—as individuals age, they and their peers go through experiences that bring these topics to the forefront in their lives.

Where do people hear about carrier screening?

Participants learned about recessive genetic disorders and carrier screening through a variety of avenues, including, in no particular order:

- The Norton & Elaine Sarnoff Center for Jewish Genetics
- A rabbi as part of **premarital counseling**
- Friends who were starting their families
- Parents and other relatives, including spouses
- Secular education: health and science classes
- Jewish education: day schools, synagogues, religious schools
- College: Hillels, Jewish sororities and fraternities
- Purveyors of genetic testing including **Dor Yeshorim** and direct-to-consumer companies
- Healthcare providers
- Internet research about pregnancy

Some of these sources of information were interpersonal—such as friends and family—while others were an organization, like a school. Still others operated at the community level, like internet forums on pregnancy. Some participants did not remember when exactly they first learned about recessive genetic disorders, but felt that they had known about it for a long time: One woman said, "I think just from Jewish programming, I'd heard of it. I knew Jewish genetic diseases were a thing."

Where do people hear about BRCA mutations?

There was a somewhat narrower range of avenues through which participants had heard about hereditary cancers compared to carrier screening. They also encompassed interpersonal, organizational and community-based sources.

- Media or literature[20]
- Family and friends who had been affected
- Jewish education: synagogue bathroom signs, educational programs
- Secular education: science classes
- Healthcare providers
- Advocacy organizations

This smaller number of sources of information about hereditary cancers (as compared to recessive disorders) might reflect the fact that scientific information about BRCA mutations is relatively newer than information about recessive genetic disorders, and community awareness is still catching up to the scientific information. The BRCA gene was discovered less than 25 years ago, and the scientific community identified the first recessive genetic disorders in the Jewish community almost 50 years ago. It also might be the case that people tend to learn about hereditary cancers later in their lives than they learn about recessive disorders.

Gender: "Nobody ever talks to a dude about this."

Even though recessive genetic disorders and hereditary cancers affect people of all genders, women were more comfortable discussing both topics. Participants indicated that in general, they felt that women are more likely to pursue medical information. One said, "I think women are far more disposed to go to an event or learn about something, I think it's much easier to reach women with medical information." Gender is an individual-level determinant of genetic health knowledge.

Both men and women suggested that women often take a more active role in maintaining the health of their families than men. Some young parents suggested that this is true with regards to carrier screening because women "take the lead" in starting a family, or "women really drive that decision." One couple we interviewed joked that if the wife had not raised the topic of carrier screening when they were planning to start a family, the husband would have eventually done so—but not until after they had already gone off birth control, later than would have been ideal. Women are more likely to report knowing someone who has had carrier screening than men: 72% of women surveyed did, compared to just 54% of men—almost a 20 point difference.[21] One expectant mom spoke frankly: "Nobody ever talks to a dude about this."

Women also knew more about hereditary cancers than men: they understood, on average, 80% of concepts related to hereditary cancers, where men understood 72%.[22] The impact of BRCA mutations on women is fairly visible in some communities—many women spoke of knowing female friends who had been affected by breast cancer—but the impact on men is discussed less frequently. One participant even commented that women are more likely to be affected by a BRCA mutation, which is a misconception—men and women are equally likely to have mutations in the BRCA genes, and they can be inherited from either parent.

Jewish 'Resume': "If you grow up in the Jewish system, you probably get it somewhere, but not everybody grew up in that system."

Since much of a person's exposure to Jewish genetic health comes from Jewish institutions, people who are not part of Jewish organizations and communities may be less likely to know about these topics. Many Jewish professionals and healthcare professionals pointed to the barriers of reaching people who don't "grow up in the Jewish system" with information about Jewish genetics, illustrating this community-level determinant of genetic health knowledge. They may be less likely to hear about Jewish genetic health in the first place and might not bring up their Jewish ancestry with a healthcare provider—even though it is relevant health information. One obstetrician-gynecologist said, "I don't have to talk to the Orthodox Jews about this, they've done all their screening. It's more with the casual Jew that this comes up in practice." Other informants corroborated this observation, saying they were less likely to hear about Jewish genetic health if they didn't grow up surrounded by a Jewish community. "When you're in an area with a low population of Jewish people, that's just not brought up," one student from the Northwest suburbs summed it up. "When you're surrounded by Jews, there's more likelihood that someone is going to know about it and be able to say in passing, and you could say, 'Hey, what's that?'"

This is one area in which the quantitative results did not align neatly with the interview and focus group data. Disentangling the influences of various aspects of Jewish background on knowledge of genetic health proved challenging. While both community leaders and laypeople observed that individuals who were "casual" Jews would be less likely to understand Jewish genetic health, the survey findings did not support that observation across the board. We were surprised to find that frequency of participation in Jewish community activities, as measured by our survey instrument, was not related to likelihood of knowing someone who has gone through carrier screening or to knowledge of recessive disorders or hereditary cancers. Additionally, the survey data

indicated that people in interfaith relationships were likely to know just as much about recessive disorders and hereditary cancers as people in Jewish-only relationships. Some individual and community-level aspects of Jewish background are related to understanding of Jewish genetic health. Notably, people who identify as "just Jewish" tend to have lower levels of knowledge about recessive disorders than people who identify as Orthodox, Conservative, and Reform.[23]

Education and Socioeconomic Status (SES)

Like overall health literacy, Jewish genetic health literacy is related to educational attainment. Many of the participants who were most knowledgeable about Jewish genetic health had graduate degrees—some of them were healthcare providers themselves or had family members who were physicians or nurses. Many people cited college as where they first learned about Jewish genetic health.[24] Education is a multi-layered influence on health knowledge: it differs on an individual level but also represents broader social and professional networks that can shape health.

Our findings in this area are somewhat limited by the small sample size of individuals who received a high school education or less, but the challenge of reaching those individuals over the course of the needs assessment is a case in point: information about Jewish genetic health might not be reaching people who are not college-educated. Or at least, they are less likely to know someone who has undergone carrier screening. Among people 25 and older, only 57% and 60% of people with college or just a high school education, respectively, know someone who has gone through carrier screening, compared to 80% of people with a graduate school education.[25]

We were unable to directly collect data on income levels, but we suspect that people with higher household income are more likely to access carrier screening. The majority of participants in the Sarnoff Center's carrier screening program who report their income level have a household income of more than $100,000 a year. Jewish healthcare professionals shared that low-income people face various barriers to accessing information about Jewish genetics, from lack of internet access to not having medical insurance. We still have much to learn about how best to reach low-income individuals.

LGBT: "As a queer person there's a constellation of decisions you have to make."

Participants indicated that LGBT people have unique needs when it comes to learning about Jewish genetic health. In some ways, LGBT individuals planning to start a family might be more likely to seek out carrier screening, because, as one participant said, "there has to be a certain amount of intentionality" to starting a family. "It's not going to just happen." At the same time, LGBT individuals are making a lot of decisions about family planning, so carrier screening could be low priority. One woman said, "There's a whole constellation of decisions you have to make about family building and this is one of them and probably a lesser-known one." She added that resources around genetic testing tend to be "very oriented toward a straight couple."

One young woman talked through her family planning, saying, "Me and my partner have to think about, have to figure out which one of us is having kids, which might be a juncture for making a decision about genetic testing. Additionally, we have to figure out if we're going to have a known or unknown donor, both of which could be a juncture for figuring out Ashkenazi genetic testing. So all of those are moments when this information is relevant and necessary and where it would be helpful to have someone to talk through it with. And I suspect that these resources aren't reaching lots of Jewish queer people at those moments of figuring it out." LGBT individuals might often be aware of Jewish genetic health issues but might not have the resources or supports to use the information in their own family planning.

Summary

A range of individual, interpersonal, organizational, and community factors shape exposure to Jewish genetic health. People learn about recessive disorders and hereditary cancers through a variety of avenues, and what makes the information stick is often a personal connection. Understanding of Jewish genetic health differs by age, gender, marital status, education, socioeconomic status, and other factors—all of which can help inform the development of education to target different groups.

Finding 3: Multiple types of touchpoints are necessary to reach people across the lifespan

The goal of educating at-risk populations about Jewish genetic health is to help people feel empowered to use that information to make decisions to guard their own health and that of their families. One of the challenges of raising awareness about these topics is that the information becomes most actionable at specific life stages when people might not seek it out. Organizations like the Sarnoff Center face a 'Catch-22.' Should we educate people about these topics when they don't feel that they are relevant to them, or should we wait and try to reach people during the limited windows when they might act on the information? We have found that different strategies work for different people—so, in short, we should do both.

Our needs assessment participants expressed interest in a combination of educational interventions at an individual, interpersonal, organizational, and community-wide level. We can reach the most people with a two-pronged approach of community education coupled with professional education. Gearing education toward outreach through peer and family networks is also an effective strategy.

"Create a culture of familiarity."

Participants felt that since Jewish genetic health can feel complex and challenging, the best way to ensure that people seek out resources when it's appropriate is to introduce the information early. One woman said, "We need to have this conversation, so let's desensitize it. People get used to these topics and it becomes less scary." This was a common theme: the idea of introducing Jewish genetic health early on to normalize the topic. One focus group participant articulated a vision for how this could work:

> If you could create a culture of familiarity with carrier screening, so that it's in the background, and if you can create a generation where carrier screening is really normal, then by the time those people age up and are having kids, those kids are more likely to have a conversation with their children at a younger age, or whatever age they think is appropriate. So it's bookended where it starts; it's a part of normal life.

This same participant had said that carrier screening feels "scary" to most of her friends—so she is reacting to an environment in which the topic is uncomfortable and stands outside the norm. Another participant, in her mid-twenties, said it would be ideal if knowledge of Jewish genetic health could be "kind of a constant thing that's always been there" because "it would be easier to have a conversation once they hit our age." Many people used the language of 'planting a seed'—that sharing a little bit of information early on about Jewish genetic health could pay dividends later. A community-level shift could be critical to shaping health at an individual level. One recently married young woman explained how introducing the information early could lead to later health action:

> I also think it's something that takes time to process. One in four is a staggering number, and if you're planning a wedding and dealing with all of that, and all of a sudden your rabbi is like, 'Oh, FYI, a lot of people have blah blah blah, and you need to go get tested,' that's a lot to process, go do, take in the potential results, on top of everything else.

Some participants had the attitude of "the sooner, the better" when introducing people to Jewish genetic health. Several suggested reaching out to youth at Jewish summer camps, Jewish day schools and religious schools, and youth groups. Some advocated for reaching college students through Hillel and Jewish sororities and fraternities. The goal of reaching out early is not to offer specifics, but to say, "This is a thing," according to an obstetrician-gynecologist—just to introduce the idea, to plant the seed.

One woman said that, when she was in college, she would have had trouble absorbing specific information about carrier screening because she was healthy and not thinking about kids, so "that feels really far away." Many participants suggested offering more specific information starting in the mid-to-late twenties because that, they said, is when people might be starting to think about having a family.

Participants also suggested reaching out to young couples—either around their wedding or afterward when they might be thinking of getting pregnant. They did note that there might be barriers to reaching this population with information. For example, many Jewish young adults do not engage with Jewish organizations after college, so for some participants, other avenues would be most appropriate for reaching them at that point in their lives—like outreach through their medical providers.

Professional education: "Reach the people who meet with the people."

Sometimes, the best way to reach at-risk individuals is indirectly, through their healthcare providers and clergy, harnessing the role of institutions to shape individual health. As one social worker put it, "This is an issue where the more that you reach the people who meet with the people—so doctors, rabbis, clinicians, nurses," you can "help them think through when to make those referrals." Many participants said their healthcare providers, rabbis, and therapists were useful source of information about health—and some even specifically shared that their doctor or rabbi had walked them through Jewish genetic health issues. They trust these individuals to be authorities on these topics. One young woman said, "If there's a professional for something, I'm going to go to that professional."

"What are you thinking about a family?"

Participants noted that clinicians and rabbis have a unique role in starting conversations about family planning and family health history. An obstetrician-gynecologist said that she often starts those conversations with patients. "I'm like, 'What you are thinking about a family?' And I get to ask this—in another setting this would be really rude—but I'm your gynecologist. I get to ask you when you're going to have babies, or if you're going to have babies." Hereditary cancers and family health history come up with other clinicians and rabbis too. One therapist said that she has had several patients raise the topic of BRCA mutations with her when they had a cancer diagnosis in the family.

"Doctors should be talking to their patients."

Most frequently, informants who said they would want to hear about Jewish genetic health from a healthcare provider mentioned primary care or women's health providers. But participants also reflected on how other specialists—for example pediatricians, neurologists, and dermatologists—might be useful sources of information.

Unfortunately, not all physicians feel prepared to have these conversations. One specialist said that she learned more about hereditary cancers from accompanying a friend to a genetic counseling appointment than she had in all her years of medical training and practice.

Participants also mentioned that sometimes they felt physicians didn't have time to answer their questions, or didn't explain things in a way that they could understand. Healthcare providers often have very limited time per appointment to address a wide range of health-related questions, so it may be challenging to fit genetic health into the conversation.

"People may be sharing with their social worker, psychologist, psychiatrist, where they are at in their lives."

One unexpected finding was that Jewish genetic health can come up in therapy. Therapists could be a source of information both for individuals thinking about having children and for individuals managing cancer in their family.

"Ideally, it would be discussed with the rabbi before you got married."

For couples who get married by a rabbi, premarital counseling is a logical time to raise the topic of carrier screening. However, participants described variability in how rabbis approached the topic. Some rabbis insisted that couples they marry go through carrier screening, some suggested it, and some did not even bring it up. Some rabbis felt adequately prepared to discuss the topic with couples they married, but others weren't sure how to start the conversation. One rabbi shared her line of thought:

> The rabbis, we could tell our couples, "Before you get pregnant, go to your OBGYN." But I don't know what to say: How early? When? Why? What are you supposed to make the appointment for? When you call the office, it'll be embarrassing, because the office staff will be like, "Why are you making the appointment?"

This rabbi felt that she couldn't start the conversation if she wouldn't be able to provide concrete guidance to couples—she didn't want to tell them to get screening without providing any further information. Another rabbi expressed frustration about the other side of screening—what happens afterward. "I feel like I was encouraged to encourage people to get tested, but not really given any information about what happens after the testing in terms of how people process or make sense of or make decisions around the results of the testing." Both rabbis and laypeople feel that premarital counseling is an appropriate time for a conversation about Jewish genetics, but rabbis don't always feel prepared to have that conversation, and laypeople rely on rabbis to guide them.

Community education

Not everyone has a relationship with a rabbi, and not every healthcare provider has the time or bandwidth to address Jewish genetic health in depth with patients. Community education can supplement and complement professional education. Both are necessary to ensure that people feel empowered to manage individual and family health.

There is no one-size-fits-all model for community education about Jewish genetic health. When participants were asked how they would prefer to learn about Jewish genetic health, they provided a wide range of answers. One young man said, "You've got to find out what works best. There's no set script or agenda that works. And when you find something that works, that's awesome, but it's not going to work for everyone. And you need to keep on trying new outreaches, new communication tactics and methods."

Participants recommended a variety of approaches to engage constituents, themselves, and their peers:

- In-person programming: speaker events, small-group discussion events, panel events
- Virtual outreach: webinars, podcasts, email newsletters, social media, short explanatory videos
- Physical resources: flyers, pamphlets

Programming can be a good way to go in-depth about a topic, or to reach people with a little bit of information when they are at a meeting about another topic. Some participants said they thought smaller events could be a good complement to larger educational events. One participant said, "When you have a smaller group, you can engage people, the comfort and the experience is more real." Another participant suggested partnering with other organizations to present a little bit of information at their meetings: she said that if she heard about Jewish genetic health when at an event for a Jewish organization she'd feel, "I was already there, this is great, I heard a little bit about something else."

Participants cautioned that, even though Jewish organizations emphasize programming, it has limitations. "I'm not sure always that a program is the way to get people information as opposed to something that can be emailed to them, or texted to them, or they can click on it. So, if you have concrete information that you want to share, being able to put that information in a place where they can click to get it in the privacy of their own home, or on their phone" can be helpful, according to one Jewish professional.

Community education ideas

When participants envisioned the kind of education they would want to consume or participate in, they emphasized a preference for simple, actionable, and interesting information. Some examples they gave were:

In-person:

- A workshop for families to practice asking each other about family health history
- "Wine and cheese and feeling breasts"—breast self-exam workshop
- Peers who have been personally affected telling their story
- Father/son event at a brewery
- Teaching genetics and probability through games
- Explain history of Jewish genetic disorders and hereditary cancers—emphasize success of screening programs and risk-reduction options

Physical or online resources:

- Infographic comparing different types of genetic testing
- A newsletter on family health history "conversation starters"
- Family health history keeper

Overall, they emphasized the benefits of sharing information that would make them feel empowered to act—for example, rather than emphasizing risks, emphasize technologies available to mitigate those risks.

Peer education: "The number one motivator is getting people's friends to motivate them."

Many participants spoke about the power of peer education, whether that happens in a structured or unstructured setting. This can work throughout the lifespan. A youth group professional suggested that training teens to be peer educators could be a great way to get the information out to that age group. A Hillel professional said, "Having a student who has bought in and is taking the lead is the most effective way I have found to do most programming." She describes, essentially, a peer educator. An engagement professional spoke about the idea of adult lay leaders as ambassadors: even something as simple as wearing a pin at services, or at an event, announcing 'Ask me about Jewish genetics' could be an avenue for peer education.

Peer education happens organically as well—many participants' first exposure to Jewish genetic health topics was through peers. Multiple women described how they had friends with breast cancer, and how they had learned from their friends' experiences. One woman said, "I think especially in this day and age there's so much discussion around the BRCA gene and [I have] friends that are diagnosed being a BRCA carrier and their children that are now BRCA carriers." Having friends share that Jewish genetic health affects them can make it feel personal and relevant and, to paraphrase one young man's words, can be a powerful motivator.

Learning from family

Like peers, family members can introduce one another to Jewish genetic health topics in a way that makes them feel relevant and compelling. Several people suggested that the best way to reach unaffiliated young adults with information about Jewish genetic health would be through their parents or grandparents, who might hear about it at a synagogue event and then share the information with them. "If parents read about it in synagogue newsletters, they can talk to their kids about it," one mom asserted. Some even said that they might be drawn to attend an event geared toward intergenerational conversation about health: for example, two men in their late twenties suggested a father-son event at a brewery.

Family can be instrumental in increasing awareness of health risks, especially by sharing information about family health history. Family health history is an important tool in assessing risk for hereditary cancers. Physicians often ask about family health history, and many participants admitted to feeling that they had a limited understanding of their own and not always thoroughly filling out forms about it—or calling and texting family members to fill in the gaps when they went for appointments.

For a variety of reasons, seeking information about family health history can be challenging. Some barriers to learning health history can't really be overcome, including estranged family and family members with uncertain cause of death. Others, however, could be resolved through education and support. These include:

- Not knowing how to start the conversation
- Confusion about what questions to ask, and who to ask them of
- Discomfort discussing personal health issues
- No system to store, share, and update the information

Some people felt that they could readily navigate collecting their family health history, and others felt that they would benefit from a workshop to facilitate those conversations. One young woman suggested hosting an event for couples to practice asking each other about their family health history so they could then fill in the gaps by asking their families. Participants felt that a tool to record and share family health history could be useful.

Summary

We can most effectively educate at-risk families of Jewish ancestry by reaching them through a variety of avenues. This includes educating professionals and community members. Different formats and topics interest individuals across the lifespan, so developing a menu of options for education is critical. Information-sharing between peers and family members can be a powerful educational tool, especially for hard-to-reach groups.

Limitations

While our sample is broad, it is not statistically representative of the Chicagoland Jewish community. Certain populations, including Orthodox Jewish populations, have unique needs that we have not fully captured. A comprehensive accounting of the needs of observant Jewish communities is beyond the scope of this project.

Since we reached out to participants through Jewish organizations and snowball sampling, our sample is likely more educated about Jewish genetic conditions than the overall population of people with Jewish ancestry. Therefore, statistics may reflect an overly positive view of awareness of Jewish genetic disorders and hereditary cancers.

RECOMMENDATIONS

This needs assessment informs the launch of our Genetic Health Education Initiative, a three-year project designed to raise awareness about Jewish genetic health topics in both Jewish and secular settings. The goals of the Genetic Health Education Initiative are to educate the Chicago Jewish community, equipping them with greater knowledge of their genetic health risks; provide resources and support to engage their families in conversations about family health history; and ultimately lower barriers for them to seek genetic counseling and medical screenings if warranted.

The most effective health education campaigns use interventions not just at the individual level, but also at interpersonal, organizational, and community levels. We will use this principle from the ecological and determinants approach to health, coupled with the needs assessment findings, to guide the development of educational resources and supports.[26] Our recommendations cover four dimensions:

Messaging

- Emphasize empowerment and that people can act to prevent Jewish genetic disorders and hereditary cancers
- Focus on family health history (FHH): how to take an FHH, the benefits of learning about FHH
- Make Jewish genetic health personal: share how it is relevant to *my* life
- Address and dispel misconceptions about Jewish genetic health

Outreach

- Reach people where they are: go to Jewish events, emphasize peer education and education through family members
- Provide resources and support to rabbis, healthcare providers and therapists around Jewish genetic health
- Strengthen partnerships with Jewish institutions and health institutions to get Jewish genetics on the agenda

Programming

- Develop small-scale educational programs tailored to various audiences
- Design activity-based education in a variety of media, to be delivered both in-person and virtually

Assessment

- Assess educational needs of rabbis and healthcare providers, including therapists
- Assess the feasibility of developing a peer education program
- Integrate assessment of pilot educational programs into ongoing program evaluation

APPENDIX

% That Know Someone Who Has Gone Through Carrier Screening

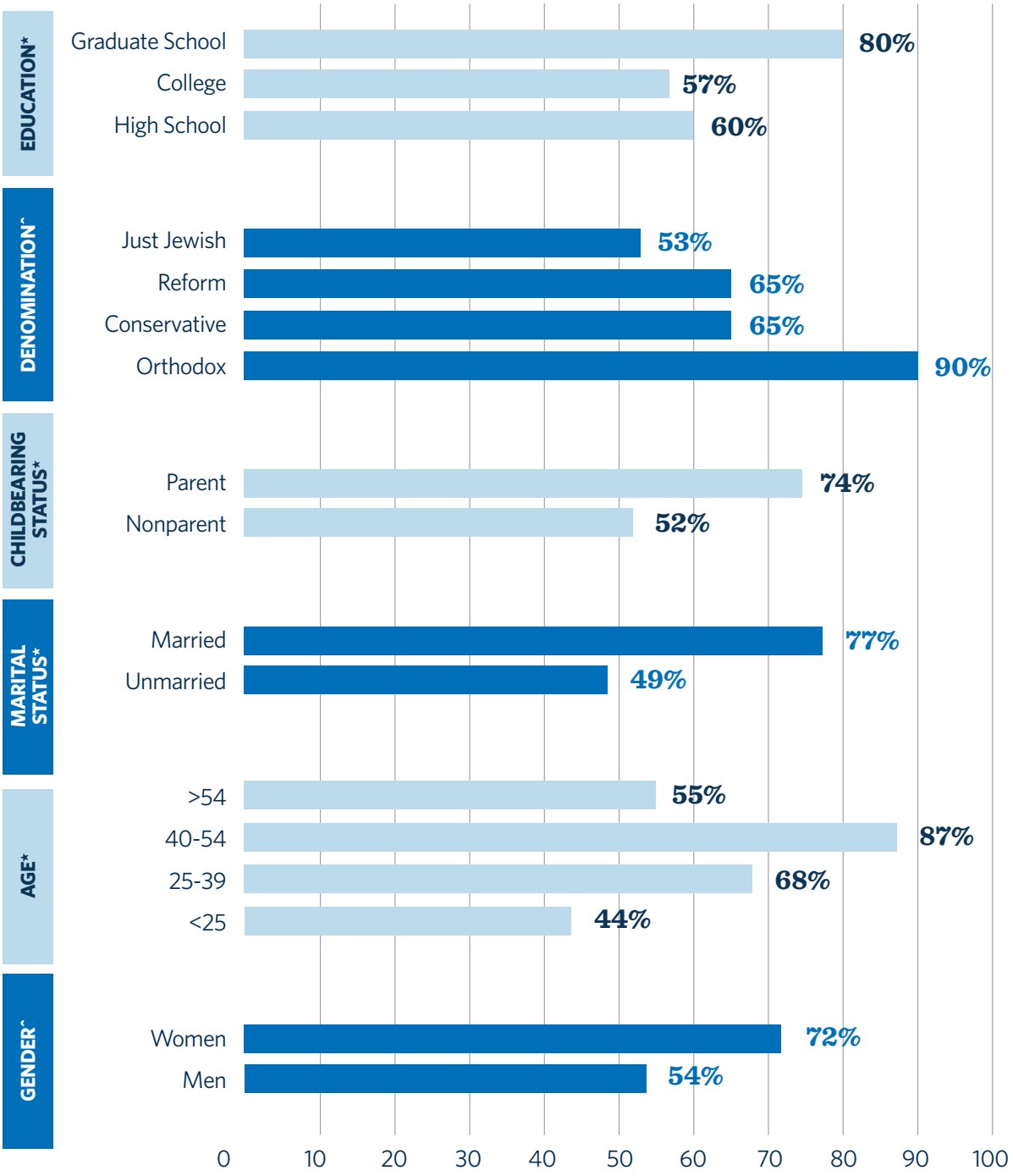

Figure 1: Differences between groups in reporting that they know someone who has gone through carrier screening

* indicates significance at the .05 level; ^ indicates significance at the .10 level

% of Hereditary Cancer Related Concepts Participants Understand

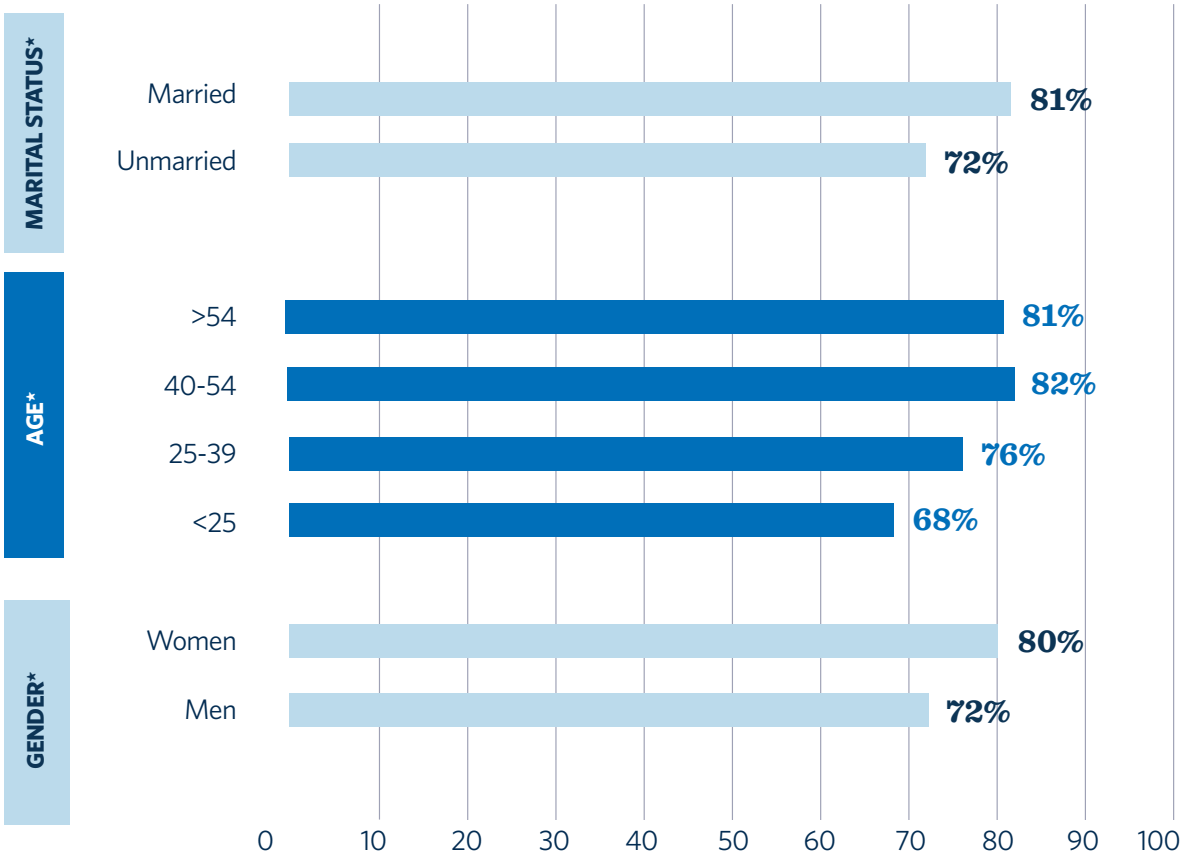

Figure 2: Differences between groups in percentage of hereditary cancer related concepts understood

* indicates significance at the .05 level

% of Recessive Disorder Related Concepts Participants Understand

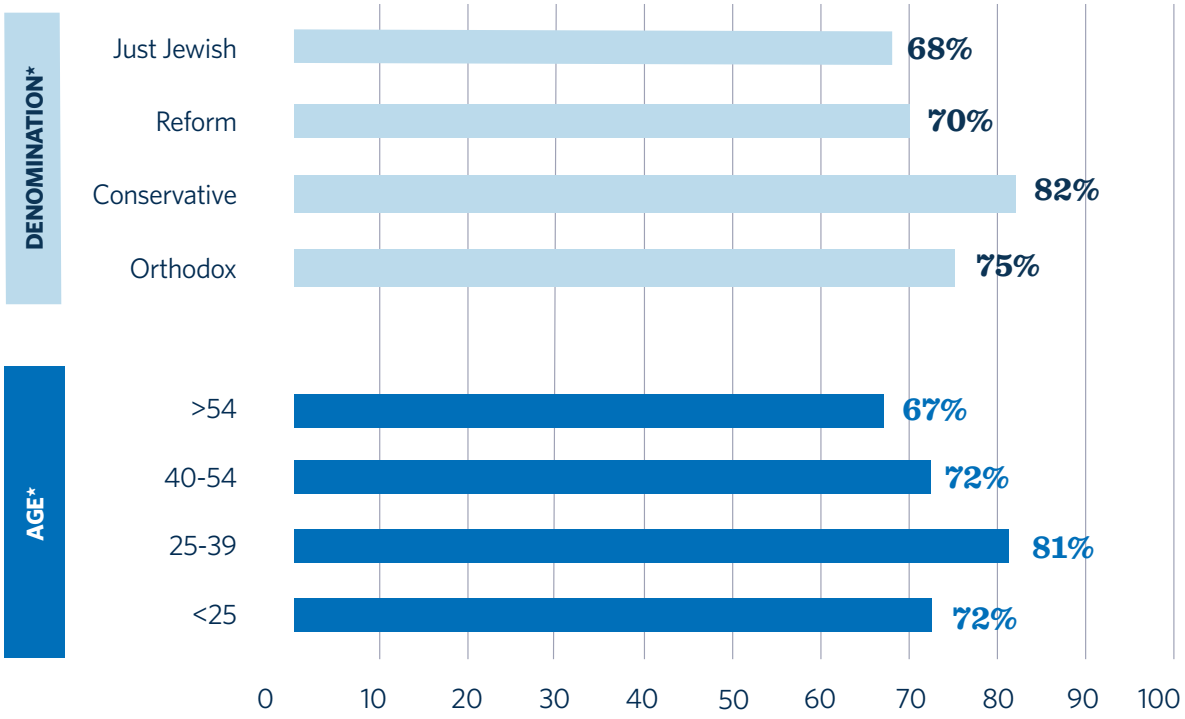

Figure 3: Differences between groups in percentage of recessive disorder related concepts understood

* indicates significance at the .05 level

ENDNOTES

1. Joel Charrow, "Ashkenazi Jewish genetic disorders," *Familial Cancer* 3, (2004): 203.

2. Yoshio Miki et al., "A strong candidate for the breast and ovarian cancer susceptibility gene *BRCA1*," *Science* 266 no. 5182, (1994): 66-71; Richard Wooster et al., "Identification of the breast cancer susceptibility gene *BRCA2*," *Nature* 379 no. 6559, (1995): 789-92.

3. Ranjit Manchanda et al., "Population testing for cancer predisposing BRCA mutations in the Ashkenazi-Jewish community: a randomized controlled trial," *Journal of the National Cancer Institute* 107 no. 1, (2014): 379.

4. "A Portrait of Jewish Americans: Overview," Pew Research Center, (Oct. 1 2013).

5. 2% identified as genderqueer or transgender

6. "Framework," Healthy People 2020. Accessed July 10, 2018. https://www.healthypeople.gov/sites/default/files/HP2020Framework.pdf

7. There are also gaps in these laws, but if people don't know they exist at all, they will not be able to weigh the possible risks effectively.

8. The American College of Obstetricians and Gynecologists, "Carrier Screening for Genetic Conditions," *Committee Opinion,* No. 691 (March 2017).

9. "Foresight Carrier Screen," Counsyl, accessed July 6, 2018. http://www.counsyl.com/provider/foresight-carrier-screen/

10. If two people are both carriers for the same recessive disorder, there is a 25% chance that any given pregnancy will be affected by that disorder. Carrier couples who don't want to take that risk have a variety of options to ensure that they have a healthy biological child.

11. For example, effective enzyme replacement treatments exist for Gaucher disease.

12. In fact, there are a variety of risk-reducing options for people who have mutations in the BRCA genes, some of which are noninvasive. The options fall into three main categories: enhanced screening, chemoprophylaxis, and risk-reducing surgeries.

13. $p<.01$

14. $p<.05$

15. $p<.05$

16. $p<.01$

17. $p<.05$

18. $p<.05$

19. $p<.05$

20. A few participants mentioned specifically that they learned about BRCA mutations from Angelina Jolie's choice to undergo risk-reducing surgery in 2013. Jolie shared her experiences in the media to raise awareness about hereditary cancers.

21. $p=.06$

22. $p<.05$

23. $p<.05$

24. There may have been some confounding by age because older people tend to have achieved higher levels of education, but this effect held when we eliminated participants below age 25 from the analysis.

25. $p<.05$

26. The ecological and determinants approach to health considers various dimensions, from the individual level to the population level, that affect health and access to health information. We adopted this approach from the Healthy People 2020 Framework.

GLOSSARY TERMS

American College of Obstetricians and Gynecologists: A professional organization of women's health care physicians that advocates standards of practice, offers continuing professional education and promotes public awareness of women's health care issues.

BRCA1* and *BRCA2: Two genes that, when functioning typically, play a role in preventing cancer.

Cancer genetic testing: This type of genetic testing is designed to provide information about mutations that may increase a person's risk for cancer.

Cancer risk assessment: A clinical service that involves meeting(s) with a genetic counselor to discuss family history, possibly genetic testing, and recommendations for managing cancer risk.

Carrier: Someone who has one mutated copy of a gene and one normally functioning copy. Usually, carriers of recessive disorders do not have symptoms.

Carrier couple: When two people plan to have children together, or have children together, and both carry one copy of a mutation that causes the same recessive disorder, they are referred to as a "carrier couple," meaning that they risk passing that genetic disorder on to their offspring.

Community needs assessment: This type of information-gathering project involves community stakeholders in identifying areas for improvement and as well as assets that might aid in improving community well-being.

Community screening programs: Starting in the 1970s, Jewish community organizations began to offer screening for recessive genetic disorders. In general, community screening programs offer opportunities for low-cost testing to identify individuals at risk of, or affected by, disease.

Cystic fibrosis: A recessive genetic disorder that causes abnormally thick mucus production, affecting the function of the lungs, pancreas, and other organs.

Direct-to-consumer (DTC) model: This model offers individuals health information directly from a commercial testing company, without the guidance or support of a healthcare provider.

Dor Yeshorim: Dor Yeshorim is a carrier screening program that primarily serves observant Jewish communities. Rather than releasing results to participants, Dor Yeshorim maintains a database of test results used in the matchmaking process to avoid pairing carrier couples.

Ecological and determinants approach to health: This framework uses various dimensions of experience in order to examine their individual and combined influence on health.

Familial dysautonomia: A progressive recessive genetic disorder that affects the nervous system.

Focus group: A meeting of a cohort of individuals to discuss their opinions, understandings, and attitudes about a topic for qualitative research purposes. Focus groups usually involve a guided group discussion.

Health determinants: As defined by the Office of Disease Prevention and Health Promotion, these include personal, social, economic, and environmental factors that influence health status.

Healthy People 2020: This initiative sponsored by the US Office of Disease Prevention and Health Promotion involves a process of goal setting for national health and ongoing measurement of objectives to be met by 2020.

Hereditary cancer syndromes: When cancers in a family are strongly linked to an inherited genetic mutation, those cancers are said to be part of one of a number of hereditary cancer syndromes.

Informants: Informant, in this context, is another word for participant: informants include individuals who participated in an interview, focus group, and/or survey.

Lynch syndrome: A heritable disorder that increases risk for several types of cancer, including colorectal and other gastrointestinal cancers.

Premarital counseling: Often, before a couple gets married, they will meet with their officiant or a counselor to discuss topics that will likely come up in their marriage, including finances, beliefs and values.

Semi-structured interviews: This technique of interviewing involves asking a series of open-ended questions. This method is often used in the social sciences and produces rich qualitative data.

Single gene disorders: This type of genetic disorder is caused by a mutation in a single gene, among the smallest units of genetic information.

Snowball sampling: Snowball sampling involves asking informants to refer individuals in their networks for participation, for example by inviting a friend to a focus group or sharing a survey link through Facebook.

SPSS: A software package used for statistical analysis.

Tay-Sachs disease: An incurable, untreatable, progressive recessive genetic disorder that is usually fatal in childhood. Incidence of Tay-Sachs disease has historically been higher in the Jewish community than the general population.

X-linked disorders: Disorders that are caused by mutations carried on the x chromosome; these disorders are generally passed from a carrier mother to her son(s).

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