GENOMIC LITERACY, EDUCATION, AND ENGAGEMENT (GLEE) INITIATIVE
2017 STRATEGIC VISIONING MEETING

Community-Public Working Group

Introduction

Genetic and genomic information (GGI) is becoming increasingly important and ubiquitous. At one time, interest in and access to GGI was limited to those engaged in basic science and clinical research. Today, one can scarcely turn on the television, go to a movie, or read popular media and not have some exposure to genetics, genomics, and DNA. Although GGI seems to be more and more infused in public discussions, the level of "public" understanding has not significantly increased. Studies have shown that the general public has some familiarity with genetic and genomic terms, but major gaps exist in their understanding of basic genetic concepts (reviewed in Kaphingst, forthcoming). Research into public understanding of genetics and health has uncovered that public understanding can be influenced by a number of factors, including their understandings or beliefs about modes of inheritance, social relationships, familiarity with a particular condition, etc. (Condit, 2010). In order to ensure that members of the public are prepared to make informed healthcare decisions, it seems clear that we need to gain a better understanding of individuals' knowledge and skills related to genetics and genomics (Green et al., 2011; Hurle et al, 2013).

In order to address the needs of the "public" with regard to GGI, we must first acknowledge the diversity of individuals and groups who make up the "public." In the United States, the "public" ranges from educated professionals to those with little formal education; from native and non-native English speakers to those with limited oral English skills and/or literacy skills in their native language; from those who are facile users of technology and have high levels of access to it (e.g., computers, mobile devices, and the Internet) to those who do not; and to many others across the "K-to-grey" age spectrum. In recognizing this diversity, we must also account for the diversity of needs with respect to GGI. In many cases, GGI is ascertained on a need-to-know basis or can be labeled as "just in time" information (S. Mann, personal communication). Individuals faced with genetic/genomic testing, diagnosis of a genetic disorder, or contemplating direct-to-consumer testing may be more compelled to acquire GGI. Even for those with a need-to-know, challenges still exist to obtaining GGI such as: where to find scientifically-based, factual information; how to find information that they can understand and act on; and, answers to concerns about privacy or negative impacts on health insurance, etc.

The Institute of Medicine defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman et al., 2004). The report operationalized this type of literacy as consisting of oral literacy (listening and speaking skills), print literacy (reading and writing skills), numeracy (basic quantitative skills), and cultural and conceptual knowledge. It is notable that approximately 36% of adults in the U.S. have limited health literacy (Kunter, Greenberg, Jin, Paulsen, & White, 2006). Given the documented lack of public knowledge about GGI, one can extrapolate that the lack of genetic/genomic health literacy is much more profound.

State of the Field: Inventory of Existing Resources/Programs

To initiate an inventory of GGI resources for the public, members of the Community-Public Working Group provided information about the GGI resources they use (see **Appendix A**). They listed websites, stories, magazines, books, libraries, and videos. These resources include materials they use with members of the public as well as resources they use as background information for themselves when developing GGI resources they produce for local use.

In talking with Working Group members and others, we found that many people and organizations create their own GGI resources/materials for use with the public and distinct communities. This is due to a perceived lack of readily available, appropriate materials and/or a need for materials tailored to their local population. In addition, there is a wealth of materials related to genetics/genomics in both the popular media and in science media for the lay public. These factors make it almost impossible to accurately inventory the available resources. We thus identified a need for a trusted, online "repository" of links to reputable websites with genetics and genomics educational materials and resources.

Gap Analysis

From December 2016 to February 2017, the Community-Public Working Group used convenience sampling to disseminate brief surveys to (a) community leaders and (b) community members who are in our networks. Over 300 individuals from 25 states responded: 102 community leaders and 233 community members. The community leaders indicated that they represent communities at the local, state and national levels. Respondents to the community member survey ranged from middle school age to over 80 years old. Their educational level ranged from those still in secondary school to those with professional degrees. The majority live in a large or medium-sized city. All races and ethnicities were represented with the largest number of respondents identifying as Black/African American and White. The surveys and complete data are available in **Appendix B**.

What people would like to learn about DNA and Genes. Respondents were asked to indicate up to 5 topics related to "DNA and genes" (from a list of 14) that they or their community would most like to learn more about. Although the topics differed slightly in ranking, the top five topics were the same for both groups of adults. Youth had some similar interests but also several different ones. (see Table 1, below).

Table 1: Top five topics that community leaders thought would be of highest interest to members of their communities, and top five topics that adults and youth would like to know more about, related to the role of DNA and genes.

Rank	Community Leaders	Adults	Youth (18 & younger)
1	Disease diagnosis & treatment	Disease prevention	Disease prevention
2	Disease prevention	Disease diagnosis & treatment	Addiction
3	Disease risk	Disease risk	Ancestry
4	DNA/genetic testing	Ancestry	Aging
5	Ancestry	DNA/genetic testing	Forensics/Law enforcement; Disease risk

How people would like to learn about DNA and Genes. Respondents were next asked to indicate the top 4 ways (out of 12) they or members of their community would most like to learn about these topics. The Internet received the highest ranking by all three groups (see Table 2, below). The "science center, science museum, zoo" ranking by youth may have been influenced by the fact that most respondents in this age category were participating in a science center program.

Table 2: Top five ways community leaders thought members of their communities would be most likely to learn about DNA and genes, and top five ways that adults and youth said they would like to learn about these topics.

Rank	Community Leaders	Adults	Youth (18 & younger)
1	Internet	Internet	Internet
2	Social media	Reading – book, magazine, newspaper	Movie or YouTube
3	Healthcare provider	Movie or YouTube	Science center/museum, zoo
4	News media – TV, radio	Educator	Social media
5	Educator	Healthcare provider	Educator

What about DNA and Genes is most exciting. In an open-response question, respondents were asked what about DNA and genes is most exciting to their community (for leaders) or to themselves (for community members). The top themes for each group are listed below (percentage of respondents for each theme and illustrative responses for each are in **Appendix B**).

<u>Community leaders</u>

1. Understanding disease risk, diagnosis, and prevention
2. Treatment for disease
3. Ancestry

<u>Adult community members</u>

1. Relationship between genetics and health
2. Ancestry
3. Environment, lifestyle and genes
4. Ongoing research/information

Youth (under 18)

1. Form and function of DNA
2. Heredity
3. Biotechnology

Concerns about DNA and genes. A second open-response question asked respondents to indicate what might concern their community about DNA and genes (for leaders) or that worries them about DNA and genes (for community members). The top themes for each group are listed below (percentage of respondents for each theme and illustrative responses for each are in **Appendix B**).

Community leaders

1. Fear of discrimination, and distrust of authority and safeguards to protect genetic/genomic information
2. Testing processes and procedures and anxiety about results
3. Equity in access to testing and treatment

Adult community members

1. Unethical or profit-based use of genetic information
2. Genetic engineering and ethical issues
3. Heritability of diseases
4. Healthcare coverage and genetics-related discrimination
5. Genetically Modified Organisms (GMOs)

Youth (under 18)

1. Heritability of diseases
2. Ethical issues

Proposed Action Plan

There are many directions that the GLEE Initiative could take with respect to public literacy in genetics and genomics. The data we collected in the survey pilot indicate that members of the public are most interested in genetics and genomics in relationship to health. This finding is supported by research showing that the public is primarily interested in genetics knowledge that is of practical relevance to them (Emery, Kumar, & Smith, 1998; Smerecnik et al., 2008). Conversations with the Working Group members about the Resource Inventory also indicated that efforts are needed to support those who are engaged in educating the public. The Community-Public Working Group recommends nine actions to address both of these "audiences". These recommendations are listed below in timeframes of 6 months, 1 year, and 2-5 years. For each recommendation, it will be important to determine the resources needed to carry it out and thus the feasibility and timeline for implementation.

In 6 months

1. **Establish a committee with broad stakeholder representation to guide the GLEE community-public initiative.**

Goal: Provide continued guidance for the GLEE community-public initiative, helping to ensure that it addresses the interests and needs of communities and public audiences.

Key steps:

- Create a committee structure, process, and charge (responsibilities). The committee and/or its working groups could oversee each of the recommendations outlined below.
- Identify appropriate stakeholders who can provide broad representation, building on the GLEE Community-Public Working Group membership.
- Establish regular conference calls.
- Provide compensation for committee members for whom participation would not be considered part of any paid employment they may have.

2. **Establish an online “repository” for genetics/genomics education materials and resources.**

Goal: Provide a trusted source where members of the public, those who provide educational materials and programs for the public, and others can go to find links to materials and resources on genetics and genomics from reputable sources.

Key steps:

- Identify a website to host the clearinghouse; *Unlocking Life’s Code* (unlockinglifescode.org) or the NHGRI website (genome.gov) are possibilities.
- Provide a way for visitors to easily search the materials, such as via key words.
- Widely promote and advertise the resource to audiences for whom it will be of interest.

By the end of Year 1

3. **Collect nationally representative data about “the public’s” interests and needs with respect to genetic and genomic information.**

Goal: Provide data that represent the diversity of “the public” to inform and focus the educational efforts of the GLEE Initiative and those of others.

Key steps:

- Collaborate with the CDC (which has expressed an interest in such data collection) and/or other federal stakeholders to plan and conduct the data collection via a survey and other means.
- Establish a committee to provide input on the design, methods, and instrument(s) to be used for data collection; committee members could include academics/researchers with relevant expertise as well as those representing a diversity of communities.
    - Identify the diversity of individuals from whom data will be collected – including those with limited health literacy and/or genomic health literacy – and the ways in which they can best be reached.
    - Consider utilizing a citizen science approach to collecting data.
- Identify an individual/organization to develop (with input and feedback from the committee) the research method(s) and instrument(s) and conduct the data collection.

- Broadly disseminate the findings via a paper(s) and conference presentations to appropriate audiences.

4. **Convene an annual meeting(s) on genetic and genomic literacy, education, and engagement.**

   Goal: Advance the field of genomic literacy, education, and engagement by organizing an annual conference(s) for interested stakeholders to meet, network, and learn from each other by sharing (a) materials and programs, (b) best practices and lessons learned, (c) research findings, and (d) evaluation/research methods and instruments.

   Key steps:

- Identify other conferences at which interested stakeholders – including those from the Community-Public, K-16, and Healthcare Provider Working Groups – are already gathering and consider adding a "satellite" meeting either before or after these conferences, or as a breakout session(s) (see **Appendix C** for a list of potential conferences).
- Plan the annual meeting(s) with the input and assistance of the stakeholder committee (recommendation #1).
- Provide funding for community leaders/members to participate in the conference(s), including (a) leaders of the demonstration projects (recommendation #6), (b) community leaders interested in applying to the demonstration project program, and (c) state chapter leaders (recommendation #7).

5. **Hold quarterly webinars on topics pertinent to genetics and genomics education.**

   Goal: Provide an online means for sharing (a) materials and programs, (b) best practices and lessons learned, (c) research findings, and (d) evaluation/research methods and instruments as well as provide technical support to the demonstration project developers (recommendation #6) and others.

   Key steps:

- Engage the community-public stakeholder committee (recommendation #1) in identifying presenters for the webinars.
- Archive the webinars for asynchronous viewing; e.g., on the "repository" website (recommendation #2).

6. **Support community-initiated demonstration projects that develop genetics/genomics educational methods and resources tailored to specific communities.**

   Goal: Develop and test models for educational methods and materials that are tailored to specific community's interests and needs and that are disseminated to inform others' work.

   Key steps:

- Develop the funding announcement and process in collaboration with the stakeholder committee (recommendation #1); once findings from the national data gathering (recommendation #3) become available, these can inform funding priorities.

- Provide technical assistance that supports community organizations from the application process through conduct and evaluation of their projects with the goal of building long-term community capacity and coalitions for research.
- Identify appropriate venues and means for the projects to share their findings and what they learned; provide funding for each project to present at one state-wide conference and one national conference (see example list of conferences in **Appendix C**).
- Develop a toolkit for conducting community-based genetics and genomics education research projects, based on the experiences of the demonstration projects.
- Evaluate the demonstration project program itself and its efficacy after five years.

7. Develop a GLEE Initiative network with "chapters" in each state.

Goal: Establish state-level "chapters" that promote genetic and genomic literacy, education, and engagement in their state, building state-wide capacity and methods tailored to their populations.

Key steps:

- Develop a plan and support materials for forming state-level chapters, in collaboration with the stakeholder committee (recommendation #1) and with support from the NHGRI Education and Community Involvement Branch staff.
    - Build on the organization and resources that have already been put in place for DNA Day; one of the projects for the chapters could be DNA Day activities.
- Identify champions in each state who can serve as initial organizers; these might include those who currently hold DNA Day programs, NIH Science Education Partnership Award (SEPA) projects, state/local health department genomics efforts, regional/state newborn screening programs and collaboratives, etc.
- Support these champions in forming and building a state-level organization that will promote genomic literacy, education, and engagement.
- Provide funding that the state chapters can apply for to implement activities and programs (e.g., DNA Day Small Awards).

During Years 2-5

Continue the above programs and initiate/implement the following:

8. Develop a national public relations campaign to promote the importance of genetic and genomic information.

Goal: Build awareness of key concepts related to genetics/genomics and their application to health and medicine.

Key steps:

- Explore options for collaborations with other initiatives such as All of Us, Surgeon General's Family Health History, etc.
- Raise funds to support the campaign.
    - Dream big: run a campaign during the Super Bowl, World Series, NBA finals, NHL finals, NASCAR, World Cup, and/or NCAA college basketball finals.

- Enlist a public relations firm to develop the campaign; the stakeholder committee (recommendation #1), the national data (recommendation #3), and the demonstration projects (recommendation #6) can provide input on designing the campaign.
- Work with an evaluator to develop a plan and instruments for evaluating the effectiveness of the campaign.

9. Promote and support research focused on genomic literacy, education, and engagement.

Goal: Continue to build the knowledge base on which to develop effective education methods, materials, and programs for the public, with a focus on those with low genomic literacy.

Key steps:

- Identify existing funding opportunities that can support this goal and/or that could receive additional funding to further support this goal.
- Develop new funding opportunities (e.g., citizen science projects).

Based on her review of the literature on genomic literacy and communication, Kaphingst (forthcoming) identified the following research areas and needs: (1) *conceptual knowledge:* the knowledge individuals need to act on GGI; the information individuals want to know about genetics and genomics; and the best ways to measure individuals' conceptual knowledge about genetics and genomics; (2) *literacy skills:* the ways in which a person's oral, reading, and writing literacy skills impact their responses to oral and print GGI; and the educational approaches that are most effective for individuals with limited literacy skills; (3) *numeracy skills:* the ways in which limited numeracy skills impact individuals' responses to genetic and genomic risk information; the ways in which comprehension of risk information affects an individual's actions in response to that information; and the formats and presentations of genetic and genomic risk information that facilitate an individual's comprehension of that information; and (4) genomic literacy: the ways in which individuals use GGI; the ways in which genomic literacy impacts an individual's responses to GGI; and the level of genomic literacy that is needed to act on GGI.

Summary

This paper represents many voices – those who are part of the Working Group, those who responded to the surveys, and the researchers whose work is published in the literature. As outlined in the Introduction, "the public" represents a very broad range of individuals who have similarities and differences with respect to GGI knowledge, interests and concerns. Despite this diversity, there is a clear need for a quantum increase in both general and tailored materials, resources, and programs that can educate individuals about GGI, prepare them to make informed and appropriate healthcare decisions, and support them throughout the decision-making process. Through the GLEE initiative, NHGRI is bringing together the broad range of stakeholders who will be critical to achieving this goal. Thus, NHGRI's leadership is critical to the success of this initiative.

Community-Public Working Group Members/White Paper Authors

Carla Easter, National Human Genome Research Institute (Co-chair)
Louisa Stark, Genetic Science Learning Center, University of Utah (Co-chair)
Elizabeth Cohn, Columbia University
Cindy Encarnacion, Saint Louis Science Center
Marnie Gelbart, Personal Genetics Education Project, Harvard University
Ella Greene-Moton, University of Michigan
Chris Gunter, Marcus Autism Center and Emory University
Kimberly A. Kaphingst, University of Utah
Elissa Levin, Helix
Sylvia Mann, Hawaii Department of Health
Eru (Ed) Napia, Urban Indian Center of Salt Lake
James O'Leary, Genetic Alliance
Fahina Tavake-Pasi, National Tongan American Society
Consuelo H. Wilkins, Vanderbilt University and Meharry Medical College
Leisa Zigman, The Genome Partnership, Inc.

Appendices:
Appendix A: Resource List
Appendix B: Surveys and Survey Data
Appendix C: Potential Conferences for Hosting GLEE Satellite Meetings or Sessions

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Appendix A: Resource List

INTERNET RESOURCES

Title: Eugenics Image Archive
Link: http://www.eugenicsarchive.org/eugenics/
Description:
This site documents the American eugenics movement through 2,500+ images, primarily from the Eugenics Record Office at CSHL.

Title: Understanding Genetics: Ask-a-Geneticist
Link: http://genetics.thetech.org/ask-a-geneticist
Description:
This site takes questions about genetics from individuals from around the world and publishes responses from graduate students and post-docs in the Department of Genetics at Stanford University.

Title: iCell App
Link: http://icell.hudsonalpha.org/
Description:
iCell is an interactive simulation that allows students and teachers to explore the inner workings of a typical animal, plant, or bacterial cell. The cell can be rotated and viewed from any angle, with any layer present or removed. It is a downloadable app for multiple platforms.

Title: 23andMe Website and App
Link: https://www.23andme.com/
Description:
This is a paid service, but the website offers a lot of genetic information even without using the service, by clicking the "learn more" buttons on both ancestry and human health. For those who have been genotyped, this is a great example of making difficult concepts accessible to general audiences.
Specific pages:
genetics 101 https://www.23andme.com/gen101/

Title: Simons VIP Connect
Link: https://simonsvipconnect.org/
Description:
Simons VIP Connect is a huge effort to create mutation-specific information and portals for families with mutations that lead to autism.

Title: Genome: Unlocking Life's Code exhibition and website
Link: http://unlockinglifescode.org
Description:
Genome: Unlocking Life's Code" immerses visitors in a high-tech environment that captures the revolutionary nature of genomic science. The 4,400-square foot exhibition, which opened June 14, 2013 at the National Mall, is the product of a partnership between the National Museum of Natural History (NMNH) and the National Human Genome Research Institute (NHGRI).
Specific pages:
Animated Genome https://unlockinglifescode.org/media/animations/659#660
Brief Genome Timeline https://unlockinglifescode.org/timeline
National DNA Day https://unlockinglifescode.org/learn/national-dna-day

Events https://unlockinglifescode.org/connections/events

Title: Talking Glossary of Genetic Terms English and Spanish
Link: https://www.genome.gov/glossary/
https://www.genome.gov/glossarys/
Description:

NHGRI created the Talking Glossary of Genetic Terms to help users better understand the terms concepts used in genetic research. The resource includes images, definitions, and specialist in the field of genetics share their descriptions of terms.

Title: DNA Learning Center: DNA from the Beginning
Link: https://www.dnalc.org/
Description:

An animated primer of 75 experiments that made modern genetics.

Title: Learn.Genetics
Link: http://learn.genetics.utah.edu/
Description:

Learn.Genetics includes a wealth of easy-to-understand materials for the public; many of them incorporate multimedia, animations, and/or video. Topics relevant to genetics/genomics include basic genetics, epigenetics, precision medicine, family health history, genetic disorders, stem cells, gene therapy, and virtual labs on DNA extraction, gel electrophoresis, PCR, and DNA microarray.

Specific pages:

Tour of Basic Genetics http://learn.genetics.utah.edu/content/basics/
Precision Medicine http://learn.genetics.utah.edu/content/precision/
Epigenetics http://learn.genetics.utah.edu/content/epigenetics/

Title: Kids Health
Link: https://kidshealth.org/
Description:

KidsHealth is more than just the facts about health. As part of The Nemours Foundation's Center for Children's Health Media, KidsHealth also provides families with perspective, advice, and comfort about a wide range of physical, emotional, and behavioral issues that affect children and teens.

Title: iBiology
Link: https://www.ibiology.org
Description:

iBiology's mission is to convey, in the form of open-access free videos, the excitement of modern biology and the process by which scientific discoveries are made.

Title: Genetic Alliance Family Health History Tools
Link: http://www.geneticalliance.org/programs/genesinlife/fhh
Description:

For more than 15 years, Genetic Alliance has spearheaded an effort to promote family health history awareness and discussion both in communities and the healthcare setting

Title: Genes in Life
Link: http://GenesInLife.org
Description:

Genes in Life is a place to learn about all the ways genetics is a part of your life. On this site you will learn how genetics affects you and your family, why you should talk to your healthcare providers about genetics, how to get involved in genetics research, and much more!

Title: Diseaseinfosearch.org
Link: http://diseaseinfosearch.org/
Description:

Are you looking for disease information or support? You've come to the right place! Simply type in the name of a condition above and Disease InfoSearch will locate quality information from a database of more than 13,000 conditions and thousands of support groups and foundations.

Title: Genetic and Rare Diseases Information Center
Link: https://rarediseases.info.nih.gov/
Description:

The Genetic and Rare Diseases Information Center (GARD) is a program of the National Center for Advancing Translational Sciences (NCATS) and is funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases in English or Spanish.

Title: National Society of Genetic Counselors
Link: http://www.nsgc.org/
Description:

The National Society of Genetic Counselors (NSGC) promotes the professional interests of genetic counselors and provides a network for professional communications. Access to continuing education opportunities, professional resources, advocacy and the discussion of all issues relevant to human genetics and the genetic counseling profession are an integral part of belonging to the NSGC.

Title: NHGRI
Link: https://www.genome.gov/
Description:

The National Human Genome Research Institute began as the National Center for Human Genome Research (NCHGR), which was established in 1989 to carry out the role of the National Institutes of Health (NIH) in the International Human Genome Project (HGP). The HGP was developed in collaboration with the United States Department of Energy and begun in 1990 to map the human genome. With the human genome sequence complete since April 2003, scientists around the world have access to a database that greatly facilitates and accelerates the pace of biomedical research. The history of the HGP, the history of genomics, and the history of NHGRI, are inextricably intertwined.

Specific pages:

Partnership for Community Engagement and Outreach in Genomics https://www.genome.gov/27563809/partnership-for-community-outreach-and-engagement-in-genomics/
Your Genome and You https://www.genome.gov/27564315/your-genome--you/
Fact Sheets https://www.genome.gov/10000202/fact-sheets/
Talking Glossary of Genetic Terms (English) https://www.genome.gov/glossary/
Talking Glossary of Genetic Terms (Spanish) https://www.genome.gov/glossarys/

Family Health History Initiative https://www.genome.gov/17516481/the-us-surgeon-generals-family-history-initiative-family-history-initiative/

Title: Personal Genetics Education Project
Link: http://www.pged.org
Description:
pgEd provides informative resources on the benefits as well as the ethical, legal, and social implications of cutting edge genetic technologies.

Title: Learning Genetics
Link: http://learninggenetics.org/
Description:
Learn about exome sequencing and secondary findings.

OTHER RESOURCES

Stories and Magazines

Title: PEARLS (Positive Exposure Ambassadors' Real Life Stories) Project
Link: http://positiveexposure.org/?page_id=33
Description:
"Positive Exposure's PEARLS Project is an educational tool in which individuals living with genetic, physical, intellectual and behavioral differences blog about life from their perspective. This is a wonderful tool for classrooms, professional development, research as well as anyone interested in gaining a deeper understanding and respect for human diversity."

Title: Stories about individuals who have benefitted from genomics often from researchers, global thinkers, innovators, front-line stories.
Link:
Description:

Title: Science Journals: Science, Nature, Discovery Magazine, Science News
Link:
Description:

Books

Title: Immortal Life of Henrietta Lacks, Language of God)
Link:
Description:

Title: Language of God
Link:
Description:

Title: Library
Link:
Description:

Videos

Title: In the Family

Link: https://www.kartemquin.com/films/in-the-family

Description:

Beginning with her story of testing positive for the familial breast cancer mutation (BRCA), Filmmaker Joanna Rudnick chronicles the lives of several women currently undergoing the process of genetic testing -- following them from their decision to seek testing, through the testing process, and in the aftermath when they are coming to terms with the information they receive.

Appendix B: Surveys and Survey Data

Community Leader Survey

DNA and Genes: What Interests Your Community?

The DNA in your genes provides all of the instructions for you to grow throughout your lifetime. Genetics is the study of how genes pass from parents to children. Genomics is the study of all of a person’s genes and their function in the body.

We’d like to learn what people would like to know about DNA, genes, genetics and genomics. The information from this survey will inform development of educational materials and programs for the public.

This survey is being distributed by a group of universities, science centers, community organizations, patient support groups, and others who develop educational materials and programs, most of which are free for the public.

We invite you to participate and share your thoughts!

An electronic version of this survey can be found at
https://www.surveymonkey.com/r/Q3MX8NM

1. **Which of the following topics about the role of DNA and genes do you think members of your community would like to know more about?**

   Check the top 5 topics.

   ___ Disease prevention
   ___ Disease risk
   ___ Disease diagnosis and treatment
   ___ DNA/genetic testing
   ___ DNA/genetic testing in babies, before and after birth
   ___ Addiction
   ___ Aging
   ___ Bacteria, microbes and health
   ___ GMO’s (genetically modified organisms
   ___ Ancestry
   ___ Forensics / law enforcement
   ___ New technologies for studying DNA and genes
   ___ Similarities and differences between humans and other species
   ___ Fact and fiction about DNA and genes in entertainment (TV, movies, etc.)

2. **In what ways are members of your community most likely to learn about the above topics?**

   Check the top 4 ways.

   ___ Internet

   ___ Social media

   ___ News media – TV, radio

   ___ Movie or YouTube

   ___ Reading – book, magazine, newspaper

   ___ Educator – teacher, professor, daycare provider

   ___ Library or librarian

   ___ Science center, science museum, zoo, aquarium

   ___ Healthcare provider – doctor, dentist, pharmacist, genetic counselor, nurse

   ___ Religious institution – church, mosque, synagogue, etc.

   ___ Family or friends

   ___ Other ____

Questions 4 and 5 are optional:

4. What about DNA and genes would be most exciting to your community?

5. We recognize that different communities have had a range of experiences with DNA and genetic testing. Many scientific advances have had positive impacts on people's lives, such as those Angelina Jolie experienced with breast cancer and identifying the best drugs to treat it. However, there also have been unpardonable injustices such as Tuskegee. What concerns might your community have?

About Your Community

Is your community:

___ National
___ State-wide: which state _______________
___ Local

Please describe your community (such as, disease focus, race/ethnicity, gender identity, age range, location, etc.)

Community Member Survey

DNA and Genes: What would you like to know?

The DNA in your genes provides all of the instructions for you to grow throughout your lifetime. Genetics is the study of how genes pass from parents to children. Genomics is the study of all of a person's genes and their function in the body.

We'd like to learn what people would like to know about DNA, genes, genetics and genomics. The information from this survey will inform development of educational materials and programs for the public.

This survey is being distributed by a group of universities, science centers, community organizations, patient support groups, and others who develop educational materials and programs, most of which are free for the public.

We invite you to participate and share your thoughts!

An electronic version of this survey can be found at https://www.research.net/r/DNAandGenes.

3. Would you like to know more about the role of DNA and genes in:
Check up to 5 topics that interest you most.

___ Disease prevention
___ Disease risk
___ Disease diagnosis and treatment
___ DNA/genetic testing
___ DNA/genetic testing in babies, before and after birth
___ Addiction
___ Aging
___ Bacteria, microbes and health
___ GMO's (genetically modified organisms
___ Ancestry
___ Forensics / law enforcement
___ New technologies for studying DNA and genes
___ Similarities and differences between humans and other species
___ Fact and fiction about DNA and genes in entertainment (TV, movies, etc.)

2. How would you like to learn about the above topics?
Check up to 4 ways.

___ Internet

___ Social media

___ News media – TV, radio

___ Movie or YouTube

___ Reading – book, magazine, newspaper

___ Educator – teacher, professor, daycare provider

___ Library or librarian

___ Science center, science museum, zoo, aquarium

___ Healthcare provider – doctor, dentist, pharmacist, genetic counselor, nurse

___ Religious institution – church, mosque, synagogue, etc.

___ Family or friends

___ Other ____

Questions 3 – 5 are optional:

3. If you've looked up information about DNA and genes on the Internet, list up to 3 websites or types of websites you've visited.

____

____

____

4. What about DNA and genes is most exciting to you?

5. Is there anything about DNA and genes that worries you?

We'd appreciate knowing a bit about you.

Your responses to these questions will let us know the range of people who fill out this survey and the communities of people who were not reached. This information will not be used to make statements about a particular group of people.

What is your gender identity?

___ Female

___ Male

___ Non-binary/third gender

___ Prefer to self-describe __________________________

___ Prefer not to say

What is your age?

___ under 18

___ 19-29

___ 30-39

___ 40-49

___ 50-59

___ 60-69

___ 70-79

___ 80 or older

What is your race or ethnicity?

___ American Indian or Alaska Native

___ Asian

___ Black or African American

___ Hispanic or Latino

___ Native Hawaiian or Other Pacific Islander

___ White

___ Other (please specify) ____

In what state do you live? ________________

In what type of area do you live?

___ Large city: 500,000 or more people

___ Medium city: 250,000 – 499,999 people

___ Small city: 100,000 – 249,999 people

___ City or town with less than 100,000 people

___ Rural

What is your highest educational level?

___ Still in middle school or high school

___ Some high school

___ High school graduate or equivalent (GED)

___ Associate's degree and/or Trade/Technical/Vocational training

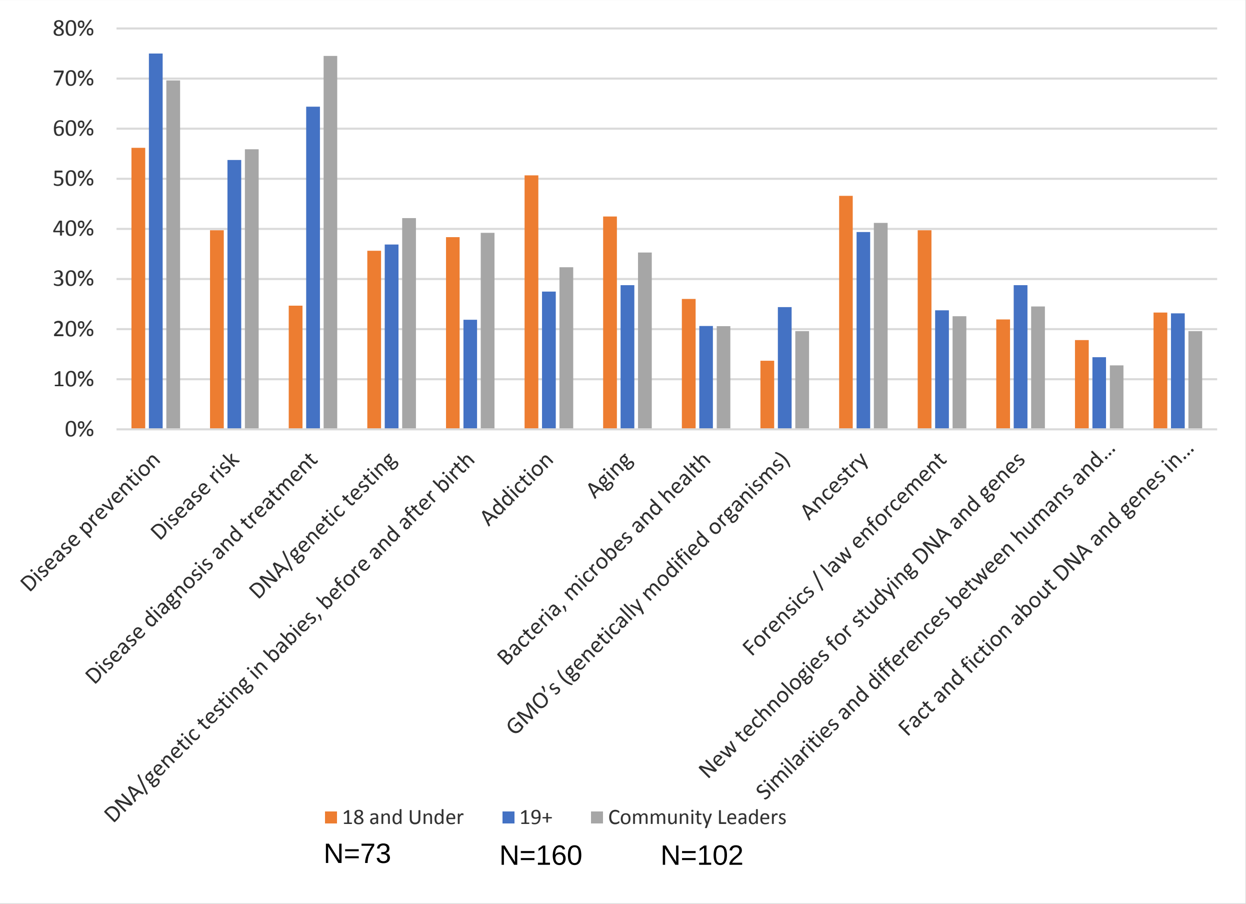
___ Bachelor's degree

___ Master's/Doctorate/Professional degree

COMMUNITY LEADERS & MEMBERS SURVEY QUESTION 1

Community Leaders Question 1: Which of the following topics about the role of DNA and genes do you think members of your community would like to know more about? *Check the top 5 topics.*

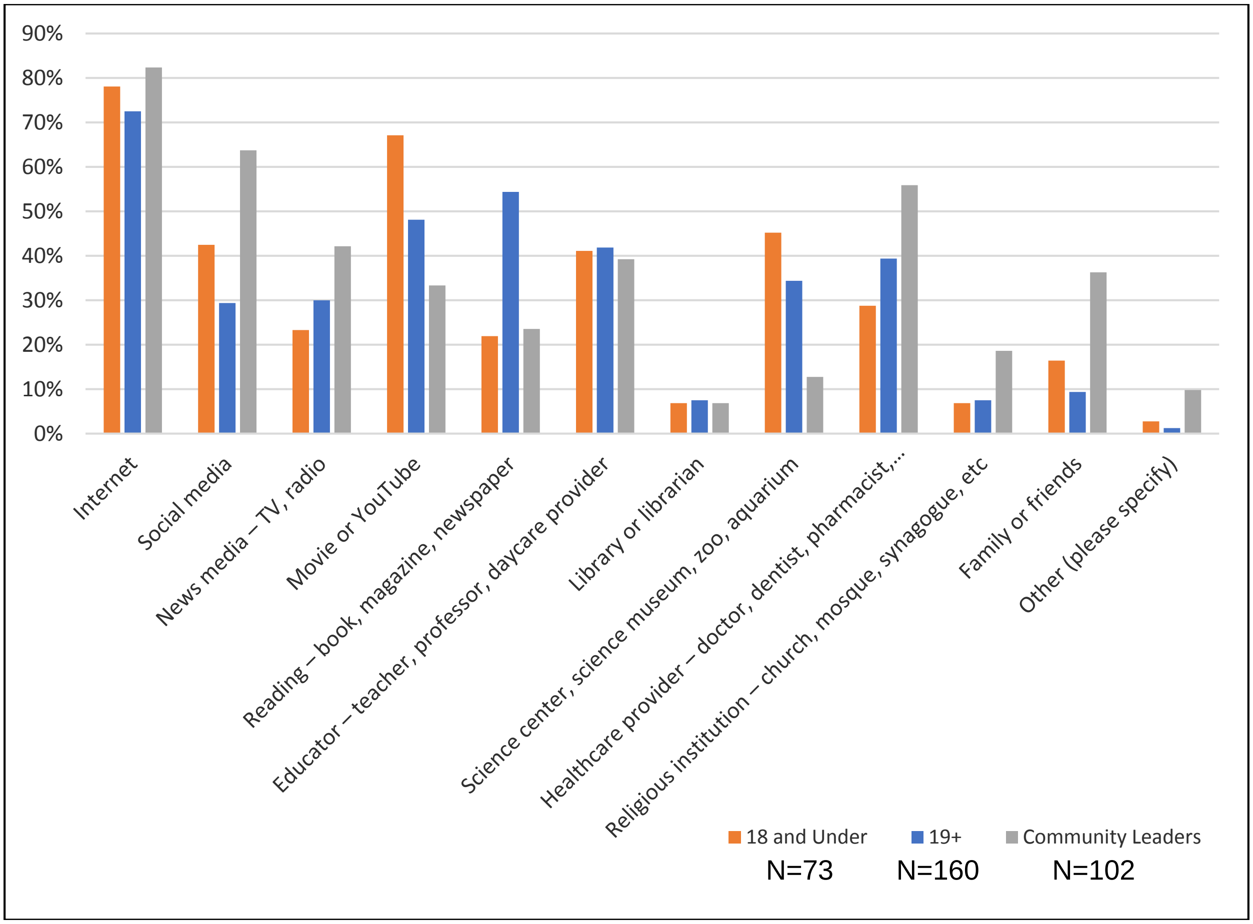
Community Members Question 1: Would you like to know more about the role of DNA and genes in: *Check up to 5 topics that interest you most.*



COMMUNITY LEADERS & MEMBERS SURVEY QUESTION 2

Community Leaders Question 2: In what ways are members of your community most likely to learn about the above topics? *Check the top 4 ways.*

Community Members Question 2: How would you like to learn about the above topics? *Check up to 4 ways.*



COMMUNITY MEMBERS SURVEY QUESTION 3

Community Members Question 3: If you've looked up information about DNA and genes on the Internet, list up to 3 websites or types of websites you've visited.

The websites most frequently listed were (in order of frequency):

1. Ancestry.com (7 responses)
2. Learn.Genetics
3. Wikipedia
4. 23andme.com
5. Journals, magazines, databases (e.g., *Scientific American*, PubMed)
6. YouTube
7. NIH
8. Search engines such as Google or Yahoo, but no website specified

For the following two open-response questions, the most frequent responses were grouped into themes. Example responses are listed under each theme.

COMMUNITY LEADERS SURVEY QUESTION 3 AND COMMUNITY MEMBERS SURVEY QUESTION 4

Community Leaders Question 3: What about DNA and genes would be most exciting to your community? (n= 75)

1. Understanding disease risk, diagnosis, and prevention (37%)
   "To see if a person is born with a trait that if exposed to a disease they are prone to catch it."
   "Basic understanding of genomics and relation to disease risk."

2. Treatment for disease (32%)
   "Most exciting would be gene therapy to treat our diseases"
   "If the defective gene that causes our rare disease could be modified to correct the defect and cure the disease."

3. Ancestry (13%)
   "Where does my lineage lead to around the world?"

Community Members Question 4: What about DNA and genes is most exciting to you?

Under 18 (n=43)

1. Form and function of DNA (51%)
   "Its bases, shapes, and codings."
   "How DNA determines everything."

2. Heredity (25%)
   "Knowing your history of who was in your family and how you are how you are today."

3. Biotechnology (7%)
   "The hands-on procedure to get DNA and the information gathered."

Over 18 (n=99)

1. Relationship between genetics and health (42%)
   "The ability to assess an individual's risk of genetic disease (with prevention as the goal)."
   "The potential to make medicine more specific and accurate, eliminating unnecessary or ineffective treatments."

2. Ancestry (19%)
   "Genetic ties to countries or cultures through your DNA."

3. Environment, lifestyle and genes (6%)
   "How our environment affects the expression of genes."
   "The impact of lifestyle on the expression of genes."

4. Ongoing research/information (6%)
   "Where we are going and what the future holds…there is much more to learn."

COMMUNITY LEADERS SURVEY QUESTION 4 AND COMMUNITY MEMBERS SURVEY QUESTION 5

Community Leaders Question 4: We recognize that different communities have had a range of experiences with DNA and genetic testing. Many scientific advances have had positive impacts on people's lives, such as those Angelina Jolie experienced with breast cancer and identifying the best drugs to treat it. However, there also have been unpardonable injustices such as Tuskegee. What concerns might your community have? (n = 67)

1. Fear of discrimination and distrust of authority, and safeguards to protect genetic/genomic information (35%)
   "Discrimination for having a pre-existing and potentially disabling condition."'
   "Hacking of genetic information and release to third parties."
   "The injustices—should we put our trust into the data and causes."

2. Testing process and procedures and anxiety about results (20%)
   "Adverse effects of testing."
   "Assuring families get a balanced view of genetic disorders at the time of a potential positive results."

3. Equity in access to testing and treatment (19%)
   "Having equity in access to information, treatments and cures across all types of Usher syndrome."
   "That the advances to help those within the community are unaffordable."

Community Members Question 5: Is there anything about DNA and genes that worries you? (n = 95)

<u>Under 18</u> (n=20)

1. Heritability of diseases (70%)
   "If you have a disease like cancer you can pass it through genetics."

2. Ethical issues (10%)
   "Making up weird things that can hurt humans"

<u>Over 18</u> (n=75)

1. Unethical or profit-based use of genetic information (23%)
   "The patenting of genetic information."
   "The medico-techno commodification of genes."

2. Genetic engineering and ethics (17%)
   "People creating designer babies."

3. Heritability of diseases (13%)
   "Possibility for disease or abnormality passed on from ancestors."

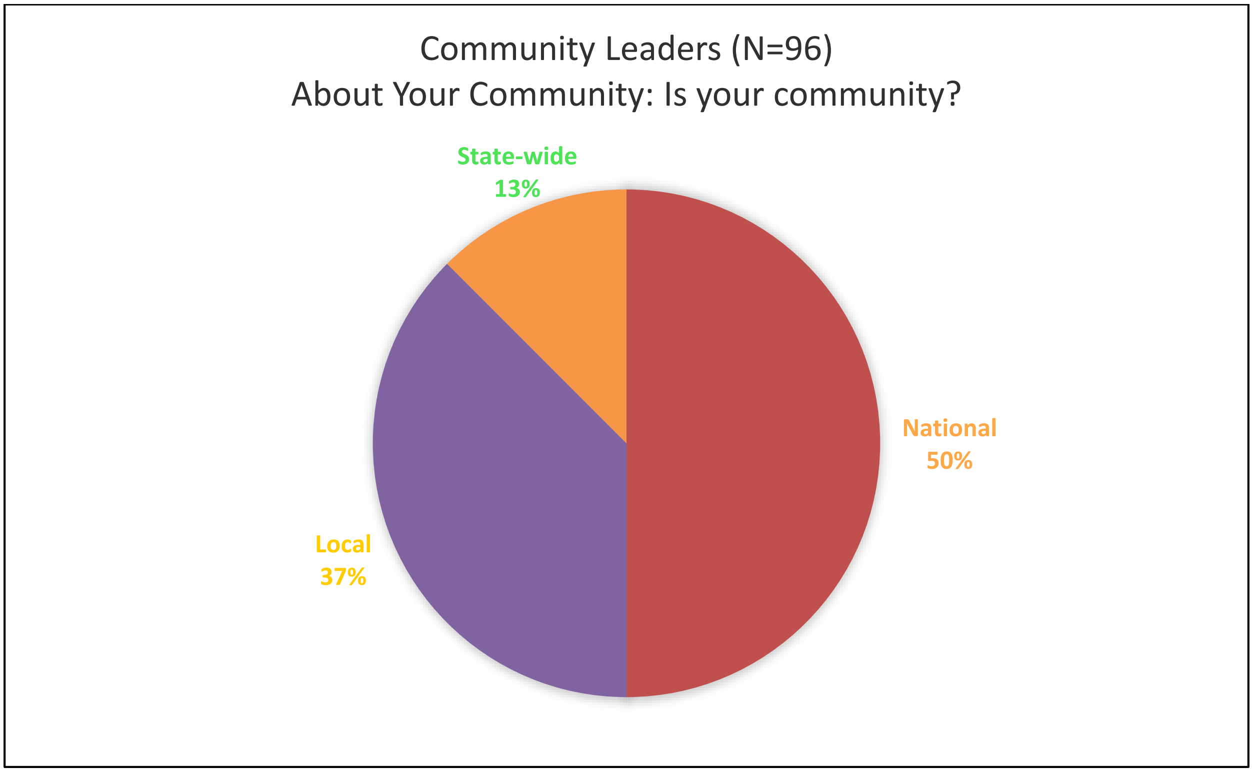
4. Healthcare coverage and genetics-related discrimination (5%)
   "If someone has genetic risks for costly diseases or conditions, will they be precluded from health insurance?"
5. Genetically Modified Organisms (GMOs) (5%)

"The manipulation and regulation of DNA in organisms for consumption. Very concerned about GMOs."

COMMUNITY LEADER DEMOGRAPHIC QUESTIONS

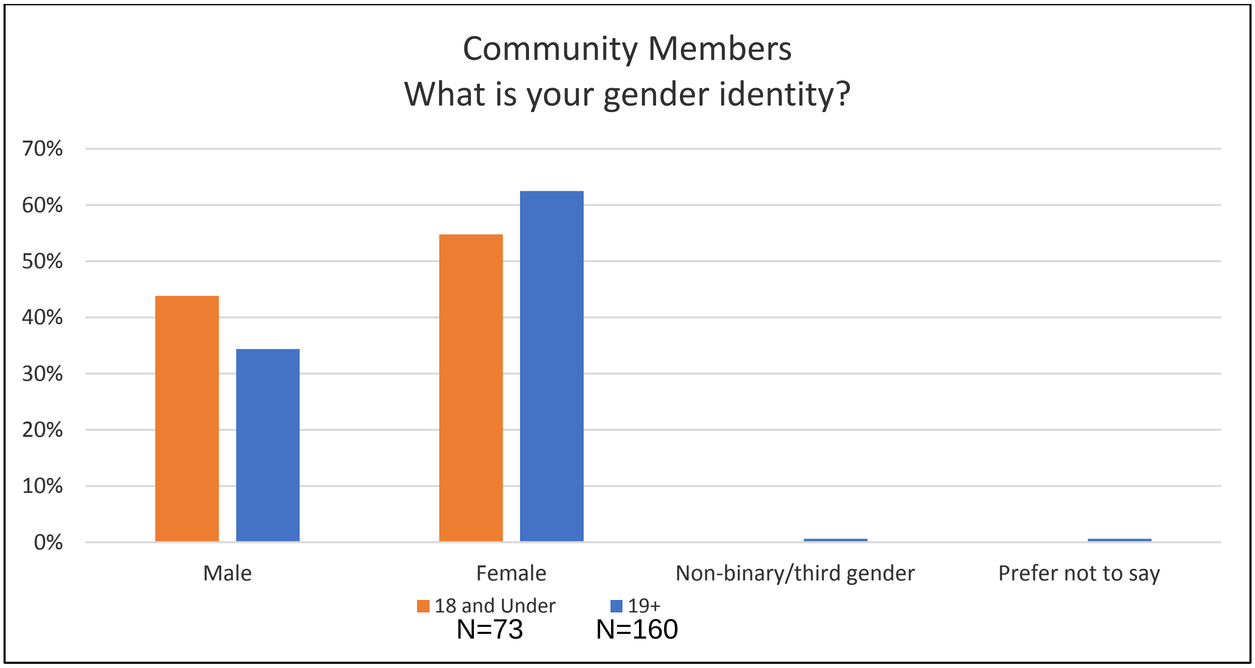
Question 5: About Your Community: Is your community?

- **National**
- **Local**
- **State-wide**

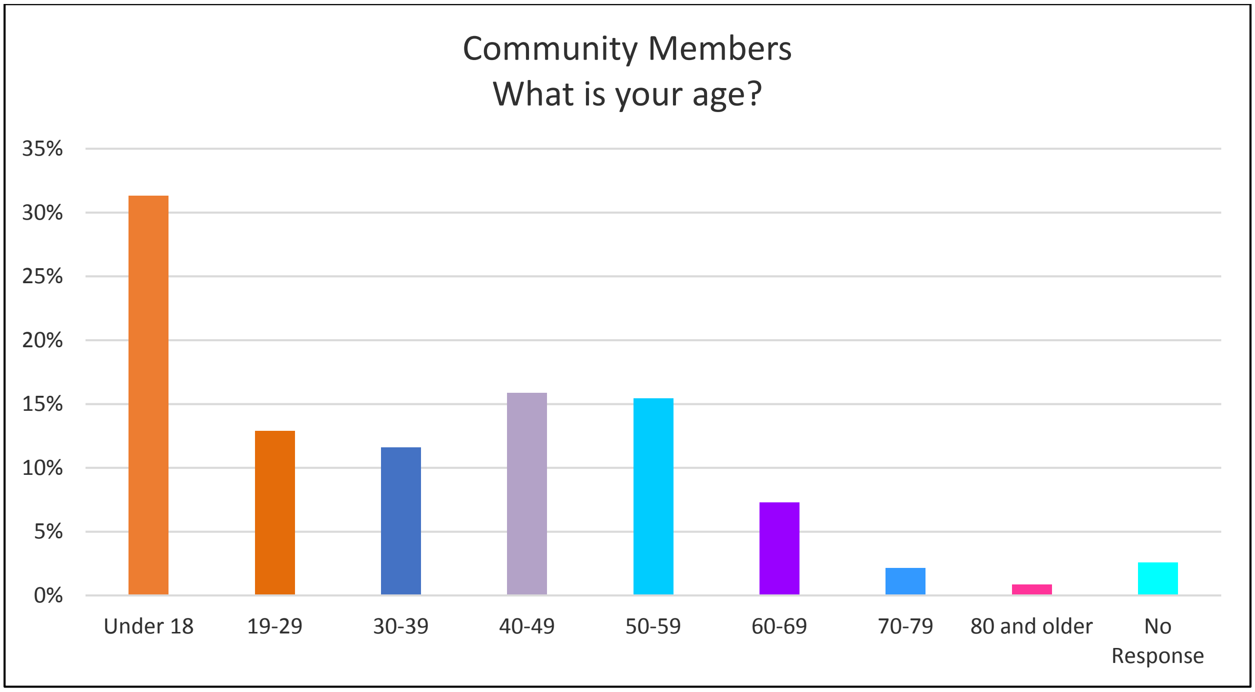


COMMUNITY MEMBER DEMOGRAPHIC QUESTIONS

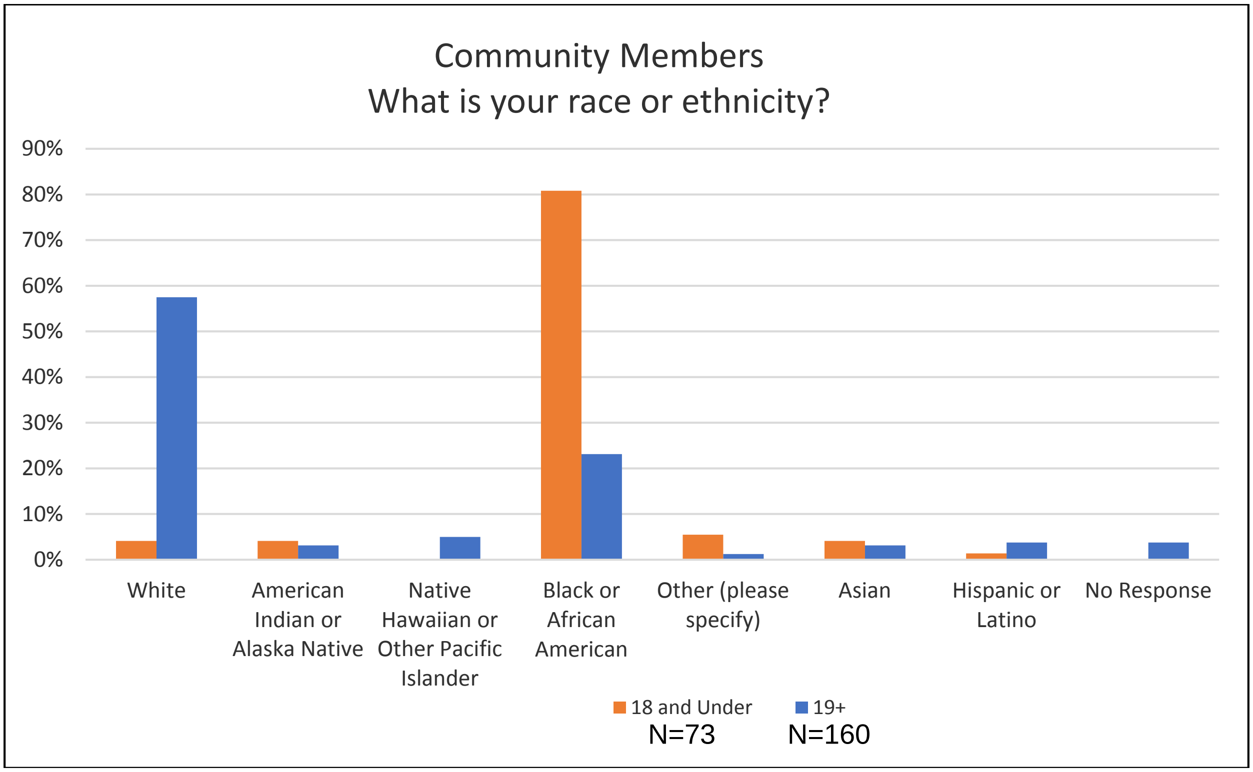
Question 6: What is your gender identity?



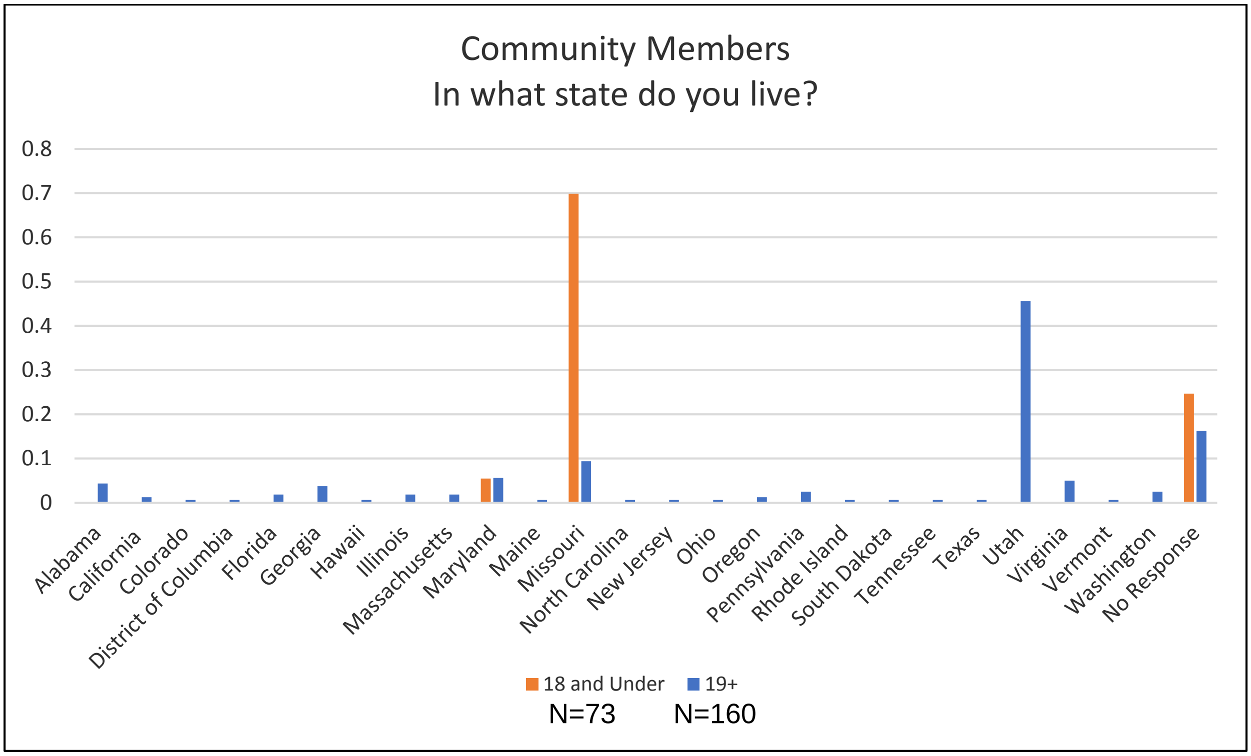
Question 7: What is your age?



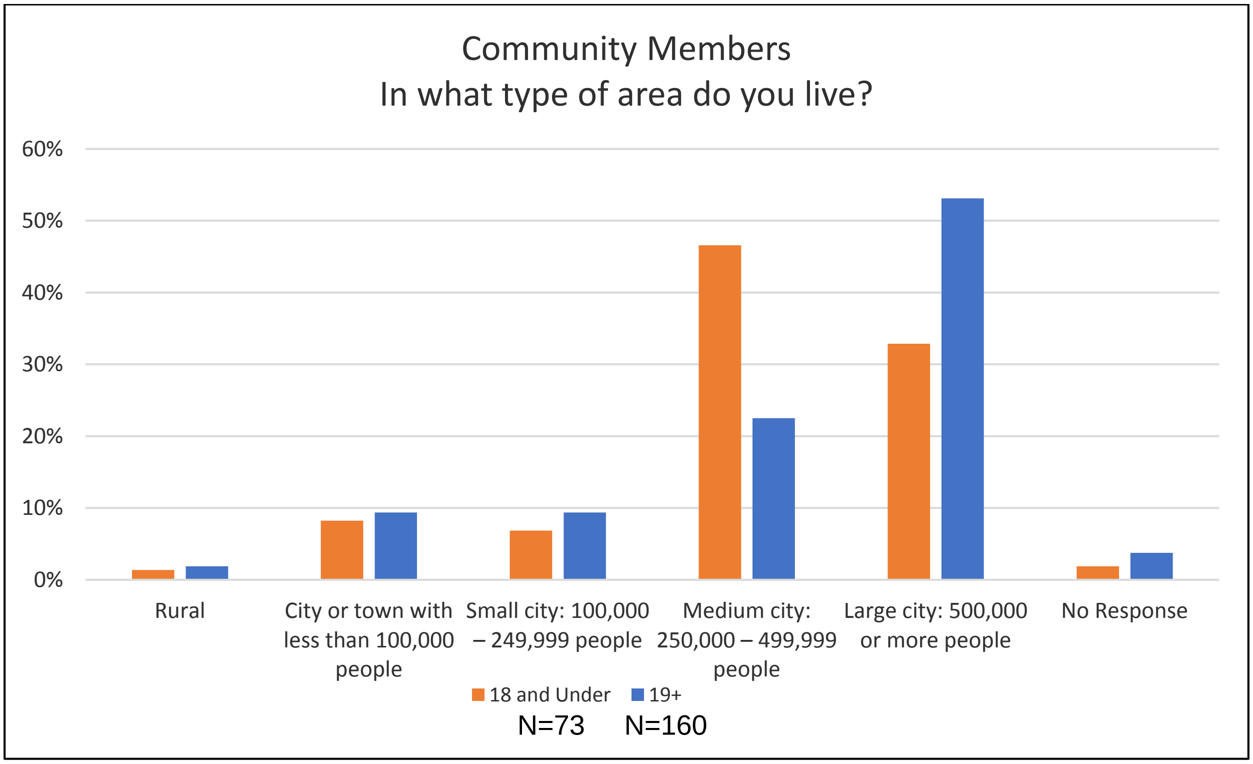
Question 8: What is your race or ethnicity?



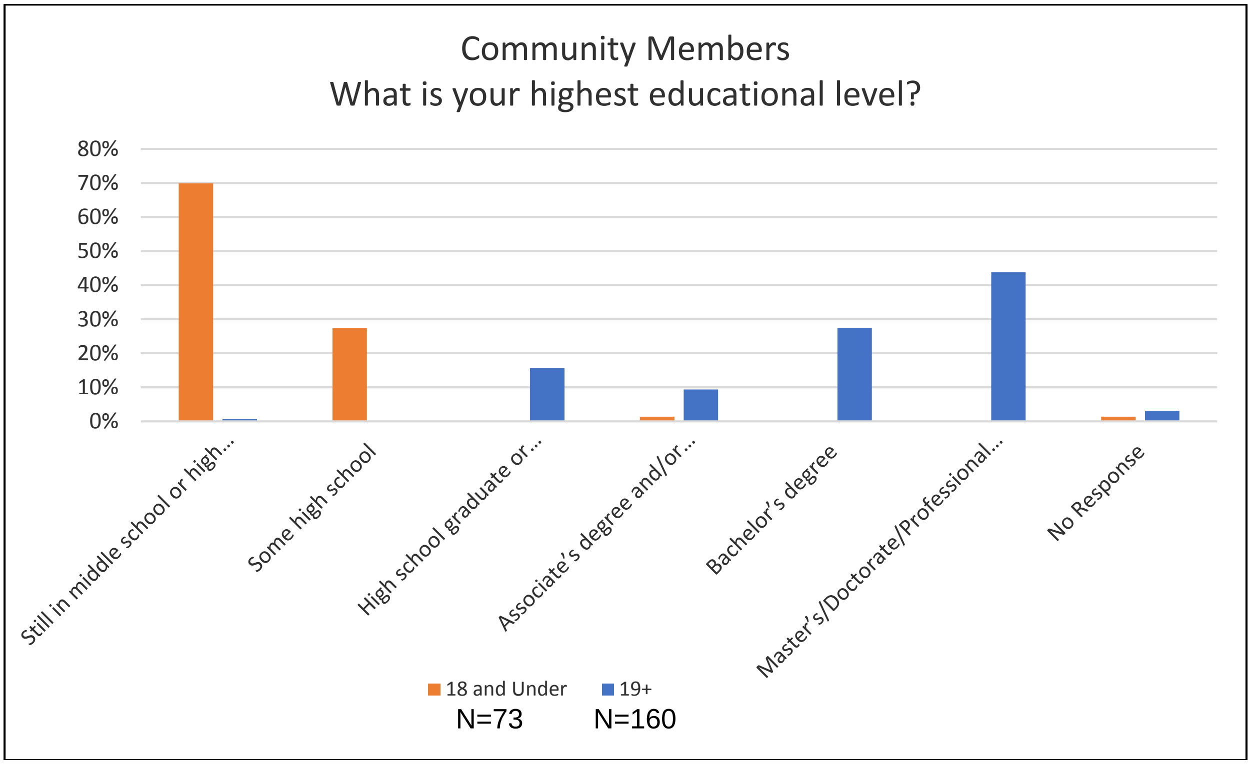
Question 9: In what state do you live?



Question 10: In what type of area do you live?



Question 11: What is your highest educational level?



Appendix C: Potential Conferences for Hosting GLEE Satellite Meetings or Sessions

(in alphabetical order)

American Association of Universities (AAU)

Association of American Medical Colleges (AAMC)

American Public Health Association (APHA) and its Genomics Forum interest group

American Society of Human Genetics (ASHG)

Association of Science – Technology Centers (ASTC)

ELSI Congress

First Americans Land-Grant Consortium (FALCON)

NIH SciEd Conference

- Brings together NIH grantees with projects focused on science education for K-12 students/teachers and the lay public; >12 of these projects focus on genetics/genomics education. All grantees funded by the Science Education Partnership Award (SEPA) program attend the conference, as well as others.

Society for the Advancement of Biology Education Research (SABER)