



Request for Proposals for
Data Collection Using



Due:
July 31, 2020

Deliver To:
PEER_Proposal@engagingresponsibly.org
Genetic Alliance, Inc.

Submissions accepted at: PEER_Proposal@engagingresponsibly.org

Black Community Development through the Promise for Engaging Everyone Responsibly (PEER)

"Black Lives Matter. We want a world that reflects that reality."

Invitation

Summary

This Invitation is for Black communities that need to provide evidence of opportunities and needs to funders, elected officials, and other decision-makers. We will provide in-kind services and technical assistance so that you can receive data from your community to state your claims and make problems and solutions clear.

Example 1:

The CDC reports that people who are *"Black have a hospitalization rate for COVID-19 approximately **5 times** that of people who are white."* It is highly likely that this is still largely under-reported. Black communities that can amass data and bring it to local health officials, the state, the country, can increase focus on these needs. The CDC says they are *"working with state, tribal, local, and territorial health departments and healthcare systems to **collect data** on the number of COVID-19 cases, hospitalizations, and deaths, and to understand which groups may be more at risk. This information can be used to better direct resources and care to address health disparities."* (Their emphasis.) Our system enables individuals to control the data they contribute, and give the community the evidence it needs to get focus, funding, and support. The Journal of the National Medical Association published a paper recently which concluded: *"Nevertheless, we remain supportive allies of all organizations concerned with communities who suffer the weight of this pandemic and any future world health disasters. Let us as human clinicians and public health professionals capture this moment of challenge and engage in thoughtful unification of effort and commit to measurable progress for as long as the need exists and certainly for the foreseeable future."*¹

Example 2:

The Joint Economic Committee of the US Senate reports: *For example, a 2019 study found that over 97% of respondents vastly underestimated the huge gap between the median wealth held by Black families (\$17,000) and White families (\$171,000)—a ratio of 10 to one. Respondents estimated the gap to be 80 percentage points smaller than the actual divide. The data reveal a much different story, with leading indicators of social and economic well-being showing that, on average, Black Americans face much more difficult circumstances than their White counterparts. For example, Black Americans take home less income, are far less likely to own their homes and live shorter lives than White Americans.* It would seem you cannot argue with such clear data. AND, it is also clear that MORE data is need for communities to be heard, and

¹ Morgan RC Jr, Reid TN. On Answering the Call to Action For COVID-19: Continuing a Bold Legacy of Health Advocacy [published online ahead of print, 2020 Jun 5]. *J Natl Med Assoc.* 2020;S0027-9684(20)30134-6. doi:10.1016/j.jnma.2020.06.010

community-specific is needed. It is good to have this data, and more needs to be known about what services are needed and how to best deliver service to alleviate these atrocities. You can use LunaPEER to gather this kind of data.²

In this Invitation we offer our data stewardship system called the Promise for Engaging Everyone Responsibly (PEER). This is a system that receives data from individuals enabled by technology called LunaDNA. We refer to this as LunaPEER, for short. This system enables individuals to share information on their own terms, thereby advancing the understanding of social impacts and accelerating the empowerment of their community. This allows communities to manage data for their own good while always retaining complete control.

A team of leaders in the fields of healthcare, science, and technology from the Black community will choose five organizations serving Black communities interested in social good to utilize LunaPEER.

Schedule

Draft Invitation released for comment: Juneteenth

Comment and Question period: June 19 - 29, 2020

Comments, questions, answers and final Invitation released: June 30, 2020

Letter of intent (optional) due: July 3, 2020

Proposals due: July 31, 2020

Applicants notified of decision: September 14, 2020

Question Submission

All questions should be submitted via email to Matthew Caffet (mcaffet@geneticalliance.org).

Please allow two business days for a response. Answers will also be posted at engagingresponsibly.com/invitation on an ongoing basis.

Background

Since 2003, Genetic Alliance has managed a member-built and -governed, cross-community data sharing network for participant-centric research on a variety of health, disease, and/or quality of life questions. Participants and their community sponsors have powered many studies, peer-reviewed papers, clinical trials, and even post-marketing drug studies. In 2008, Genetic Alliance began to expand this vision to develop improved ways for individuals to grant faster, easier, and less costly access to sensitive information in order to improve care or accelerate research. These efforts culminated in the development of a novel platform for participant-centric research networks, the Promise for Engaging Everybody in Research (PEER). PEER is an award-winning, cross-interest, program with several remarkable characteristics. The program empowers individuals to share health information, including their lived experience (called patient reported outcomes (PRO)), electronic health records (EHR), and any genetic or genomic information they may have.

PEER launched in 2011, and since then, Genetic Alliance has enabled many communities to

² The Economic State of Black America in 2020, Joint Economic Committee, US Senate.

flesh out a variety of causes, issues, conditions, questions, and campaigns, all using the PEER technology. As the system expanded, Genetic Alliance identified a need for improvements which would permit participating communities and organizations to engage their members quickly and efficiently. This culminated in the partnership with LunaPBC (a public benefit corporation) in 2019 to use their technology platform, leading to the birth of the LunaPEER system.

Today, LunaPEER seamlessly spans community creation through research and discovery (Figure 1). In addition to gathering real-world and self-reported information, the system includes advanced capabilities for capturing a variety of data types that is ever expanding. This customizable system is exceedingly easy to set up and deploy. The LunaPEER Team also offers resources to help design a study, institutional review board approval, and participant engagement science so you can be sure you are operating in full consideration of welfare and safety of your community.

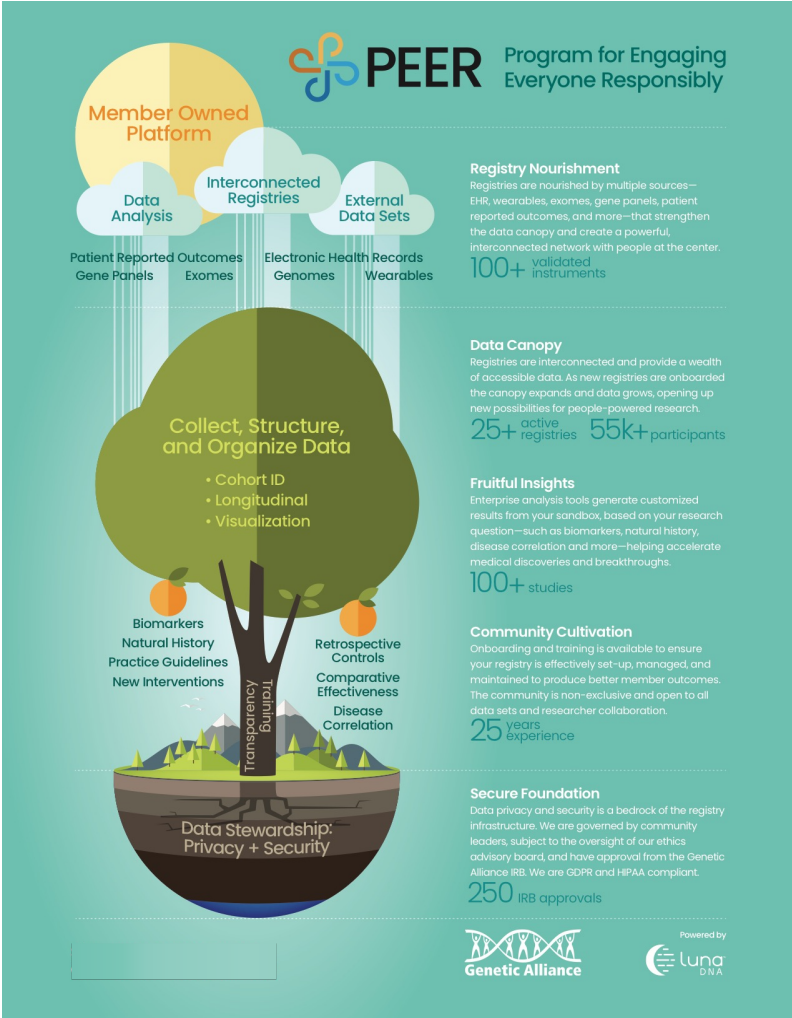


Figure 1

Award Value

The value of this award is approximately US\$30,000 in technology access and technical assistance, including:

- One-year membership in PEER at the Consortium level (See Appendix A for Membership Levels and their Features).
- Custom web landing page deployment for your community based on a pre-established design template.
- Custom on-boarding with the ability to decide what information to collect and the order in which participants experience data requests.
- Two (2) community-specific surveys, not to exceed 15 questions per survey.
- Monthly fees associated with maintaining the community on LunaPEER will be waived for 12 months from award date. See the table in Appendix B below for further details about monthly fees.

Purpose: Survey/Registry Development

A panel of leaders in the fields of healthcare, science and technology from the Black community will select five Black organizations to use the LunaPEER system to power participant-centric research. The implementation will support discovery in disparities, quality of life, education, and/or health, and put the power and control in data sharing in individuals' and communities' hands – a key feature of the platform.

LunaPEER's feature and functionality support any community seeking data-driven answers (Appendix C). Community organizations, disease organizations, and self-organized groups of people (e.g., employees of a company, members of a gym, church or temple) can use LunaPEER to conduct surveys and/or build a registry. LunaPEER includes a simple dashboard and accompanying directions to facilitate development of individual organization's or collective's LunaPEER registry. Using the dashboard and standard operation procedure, organizations and collectives determine the focus of their campaign, study, data collection and/or registry, design their landing page, and determine which common data elements³ and validated instruments⁴ to use in a data collection system, sometimes called a registry.

An example of the LunaPEER experience to a participant can be seen [by creating a general account on LunaDNA](#). We recommend all applicants visit, sign up, create a profile, and test the system to better understand what it offers, knowing that the general experience on LunaDNA is currently health focused.

Further information is here:

[Data collection by communities.](#)
[Features of the Platform.](#)

³ A **common data element** is a question, often part of a set of questions, which gathers data uniformly across studies to increase data sharing and quality.

⁴ A **validated instrument** is a questionnaire that successfully measures what it intends to measure. Such validity can be established through literature reviews, expert input, research, data analysis, and evidence of the instrument's ability to target the research of interest. It is designed to remove biases and inaccuracies potentially found in other instruments.

Organizations will be given tools to develop and implement their own LunaPEER community data collection as part of this project, for a total of five new registries. Each registry represents a mechanism for organizations to engage with their communities and power participant-centric research around health, social good, and/or quality of life, either through the creation of a registry or the release of surveys. In each registry:

- Individuals register for an account
- Individuals manage their data access preferences
- Surveys, which can include questions that are specific to the organization and questions that are generalized across the platform, serve to involve and engage participants
- Advanced data sharing including the option to connect electronic health records and upload DNA files is enabled
- Individuals can choose to share information on one or more conditions or topics, recognizing that many people experience many disparities, challenges, co-morbidities, or have an interest in sharing information on multiple topics

Eligibility

We are interested in ensuring the five awards are given to Black communities, and are diverse in multiple ways, including socioeconomic status, cause or issues, and geography. Furthermore, we are looking to find the voice of non-traditional collectives or affinity groups, (e.g. employees of companies, faith communities, gyms, day care centers, clubs, playgroups, prenatal classes, community centers and so on).

Eligible applicants include:

Any participant-generated, participant-centric, collective: community organizations, disease advocacy organizations, employee organizations, members of a gym, church, or other affinity organization whose clients/members/participants are primarily from the Black community. The collective does not need to have a brick-and-mortar presence. An individual may not apply unless they have a group of people and collaborators. Applications must be received as one file or they will not be considered.

Eligible applicants must have:

- Two (2) individuals (such as leaders of a community) to designate as the official signers and responsible parties;
- The capacity to develop survey questions specific to an issue or campaign (as a reminder, we have the infrastructure to deploy custom surveys, and a library of validated surveys, but you oversee determining the questions that would benefit your cause or community);
- The ability to engage your community, including a plan for recruitment, reflection, and follow-up;
- The ability to complete and submit the ethics oversight application (Institutional Review Board (IRB)) through Genetic Alliance's template; and,

Eligible applicants must be willing to sign the following Promise Statement:

Promise for Engaging Everyone Responsibly

The purpose of this signed promise statement is to solidify a vision in the minds of all members of LunaPEER, and to bind ourselves to this vision as a community of communities. We believe that by manifesting this promise as an explicit statement, and by signing our names to this statement, we will embolden and empower this community to become a force for change and improvement in the world.

By Signing this statement, you are affirming that:

- Communities have a responsibility to support one another. Our success and failures are intrinsically linked together, we lift each other up to the benefit of us all. PEER is built by the community for the community.*
- The true power within the community lies with the members.*
- We empower our members to control their data, and act in accordance with their wishes.*
- Every individual who provides data for research has a right to the results of that research. Built into our research processes are methods for responsibly sharing insights and research results back to the members of our communities.*
- Research we support is for the benefit of individuals and communities. We will endeavor to only ask questions that have the potential to improve the lives of a group or humanity at large.*

On Behalf of ____ (Name of Registry) ____, I ____ (Name of Individual) ____ promise to uphold the principles laid out above in this way (to be determined after the organization starts building their registry or campaign).

Accepted applicants will be expected to complete the Responsible Engagement Certificate (REC) by 12 months after the award date.

REC Criteria

1. Completion of Responsible Engagement Bootcamp (trainings for creating a data collection community ~40 hours of reading and quizzes)
2. Creation of Responsible Engagement Plan specific to individual registry
3. Human Research Protection Certificate for anyone intending to work with the data
4. IRB Approval (Genetic Alliance has an IRB that will review this as part of this award)

If you have questions about your eligibility, please contact [Matthew Caffet](#).

Awards

The LunaPEER Team will notify the five organizations that are approved on or before September 14, 2020.

How to Apply

Letter of Intent (Optional)

By July 3, please email [Matthew Caffet](mailto:Matthew.Caffet@engagingresponsibly.org) with your intent to submit. This is not binding; we just need to line up enough reviewers in advance. Include:

- Your name and contact information
- A description of the community you represent
- Any organizational name if applicable
- Why you are interested

Complete proposals should demonstrate the organization's commitment to building a survey and/or registry that is participant-centric, with a clear description of why the organization wishes to implement a LunaPEER engagement, and their capacity to do so. Proposals must use the attached template, which will ask for the following:

- Identification of the primary contacts for the project, including email and mailing address
- Four page proposal narrative (Times New Roman/Calibri, 12-point-font, one-inch margins, single-spaced).
- Resumes of key personnel who would be directly involved in this project (limited to four pages each, optional template for this is offered in Appendix D, not required)

Proposal Narrative – 4 pages maximum; must include the following information:

- Brief description of the organization or collective's mission
- Brief description of the topic of interest, disease, condition, quality of life, or campaign on which you wish to focus your LunaPEER registry
- Description of the organization or collective's draft plan to engage community, including goals, target audience, and desirable outcomes
- Description of how the organization will increase its reach, support new or existing projects, and how you/your community can improve the LunaPEER experience over the next 12 months
- Number of full and part time staff (paid or unpaid) and how they will be supported
- Budget size of your organization. If not an organization, please describe another indication of your sustainability, attach your 990 or reason for not filing one

Evaluation Criteria

A team of reviewers will be appointed for the administrative review process, making sure the applicants have included all of the necessary pieces. The LunaPEER Team will pass the eligible applications to an appointed panel of Black community leaders to make the final decisions.

The LunaPEER Team reserves the right to conduct discussions with applicants, to accept revisions of proposals, or to negotiate separately with any source whatsoever if it is determined by Genetic Alliance that an insufficient number of quality proposals have been submitted. During this discussion period, Genetic Alliance will not disclose any information regarding proposal submittals. Submit proposals to PEER_Proposal@engagingresponsibly.org.

Scoring Criteria	Points
Proposal Clarity	
How clearly does the applicant describe why they should be awarded a LunaPEER registry?	20
Capacity	
Does the applicant demonstrate adequate capacity to successfully complete the project?	25
Impact	
How well does the applicant describe the outcomes they believe a LunaPEER engagement will afford them?	20
Engagement	
How well does the proposal describe the organization and/or initiative's engagement plan?	25
Sustainability	
Does the organization and/or initiative describe a reasonable plan for continuing until 2021?	10
Total	100

The deadline for receipt of full proposals is July 31st, 2020.

For other Inquiries or Additional Information, please email [Matthew Caffet](mailto:Matthew.Caffet).

Appendix A
Membership Levels and their Features

Features and Services	Membership Level		
	Subscriber	Consortium	Governor
Membership level Fees			
Covers all services unless denoted by (\$)	per budget ¹	per budget ¹	\$50,000/year
Community creation			
Bootcamp: Step-by-step guide & training	✔	✔	✔
Enhanced Bootcamp		✔	✔
Mentor Access: LunaPEER community workgroups, listservs & shared tools	Basic	Full	Full
Recruitment: Consultation services ^{2*}	2 sessions	5 sessions	10 sessions
Recruitment: On-boarding services ^{2*}			✔
Study design & implementation			
Bootcamp: Step-by-step guide & trainings	✔	✔	✔
Enhanced Bootcamp		✔	✔
Study design: Consultation services ^{2*}	2 sessions	5 sessions	unlimited
Study recruitment: Consultation services ^{1*}	2 sessions	5 sessions	unlimited
Enrollment services: in-platform enrollment and study pre-requisites	Standard	Standard	Standard
Enrollment services: custom development/integrations		✔ (*)(\$)	✔ (*)(\$)
IRB: access to GA IRB for approval and review of submissions	✔ (\$)	✔	✔
Community Administration/Management			

Admin & Staff licenses ²	5 licenses	10 licenses	unlimited
Surveybuilder: create custom surveys, access validated instrument library	✓	✓	✓
Recontact tool: message de-identified community members (e.g. updates, data requests, reminders)	✓	✓	✓
Recontact tool: pre-create messages, schedule automatic messages		✓	✓
Community Metrics: e.g. # members, data collected, etc.)	✓	✓	✓
Support Proxy: participant-controlled enhanced access by community	✓	✓	✓
Participant Experience Customization	✓	✓	✓
Data Collection			
In-platform collection tools: full access	✓	✓	✓
Custom data collection integrations		✓ (*)(\$)	✓ (*)(\$)
Discovery (Analysis and data visualization)			
Study Admin & Staff licenses ²	2 licenses	5 licenses	unlimited
Cohort Identification Tool: search by data attributes for cohort creation	✓	✓	✓
Discovery Package: includes licenses, analysis tools, sandbox access	per package chosen (\$)	per package chosen (\$)	per package chosen (\$)
Analysis Query Tool: complex member data attribute search for deep analysis	Included with package	Included with package	Included with package
External data sets: import to sandbox	per package chosen (\$)	per package chosen (\$)	per package chosen (\$)
Integrations with external data source			✓ (*)(\$)
Custom analysis tool integrations			✓ (*)(\$)

Support			
Help Center: FAQs, Tool Guides, etc.	✓	✓	✓
Platform Chat: M-F 8am to 5pm PT, Platform technical support only	✓	✓	✓
Post-Community Launch Support: Consultations ^{2*}	2 sessions	5 sessions	unlimited
Platform Technology Consultations ^{2*}	2 sessions	5 sessions	unlimited
Platform & Program Evolution			
Pre-launch Notice & Training	✓	✓	✓
User Research Participation: help inform new features and functionality	✓	✓	✓
Product Testing Participation: help test new features and functionality	✓	✓	✓
Community Governance: help shape priorities for platform evolution	annual calls	quarterly calls	monthly discussions
Strategic Roadmap Influence: help drive decisions on platform evolution			✓

1 – See Appendix B for Subscriber and Consortium membership level fees.

2 – Additional options may be purchased for a fee without going to next membership level

* – These services may be gated by sufficient resource availability by Genetic Alliance and/or LunaPBC.

(\$) These services may have additional fees associated with them (e.g. custom development).

Appendix B

Ongoing Monthly Fees (after award ends on September 30, 2021)

Subscription Fee and Payment Terms

There are three levels of membership with associated benefits (complete benefit sheet available, but you do not have to decide now which level you will continue on in 2021).

- Subscriber
- Consortium
- Governor

Subscriber Level Fees are monthly fees based on the PEER Sponsor's organizational expenses in the previous year (line 18 of the 990 form):

Organizational Budget	Monthly Fee
< \$100,000	\$50
\$100,000 to \$500,000	\$100
> \$500,000	\$150

Consortium Level Fee is an annual fee based on PEER Sponsor's organizational expenses in the previous year (line 18 of the 990 form):

Organizational Budget	Annual Fee
More than \$1 Million	1.5% of the previous year expenses (line 18 of the 990 form) with a maximum of \$30,000
Less than \$1 Million	1.2% of the previous year expenses (line 18 of the 990 form) with a minimum of \$5,000

Governors Level Fee is an annual fee of \$50,000.

Payment

Fees will be invoiced to the billing contact of the PEER Sponsor and due within 30 days of invoice or charged to the PEER Sponsor credit card on file. Consortium and Governor Level invoices are billed as one annual payment and Subscriber Level fees are billed on a monthly basis. The initial fee will be invoiced or billed upon signing the contract.

Renewal

This agreement and associated billing will renew automatically on January 1st of each year. Subsequent year's fees will be based upon organizational expenses, as determined by total expenses on (line 18 of the 990 form).

Appendix C LunaPEER Features and Functionality



Program for Engaging Everyone Responsibly

Join the ever-growing nexus of support groups, registries and foundations building people-powered data sharing communities to uncover the solutions that matter.

FEATURES + FUNCTIONALITY

Registry Branding

Plug-and-Play Set Up

Libraries of Validated Instruments,
Surveys, and Questionnaires

Enterprise Analysis Tool

Cross-registry Data Access
and Communication

EHR Portal Connection

Genomic Information Sharing

Data Standardization

Build your registry.

Your Registry. Your Research. Your Results.



How it Works



Create a Registry

Establish and grow your registry with our self-guided, proven resource that takes you from concept to community—including IRB support, biobank resources, off-the-shelf validated surveys, and more.



Connect Health + DNA Data to Drive Research

Leverage APIs that empower your participants to securely upload and store data including electronic health records, health surveys, genomic/genetic information, and more.



Advance Science + Accelerate Health Discovery

Execute research questions and query the de-identified, encrypted data to answer your research questions and operate in compliance with GDPR and consumer privacy laws.



Reward Your Members with Shares for Sharing

Participants can earn shares for their data contribution and may choose to donate them to your organization. Proceeds earned from research flow back in the form of dividends, ensuring everyone shares in the value created.

Appendix D Biographical Sketches

Personal Statement

“Briefly describe why your experience and qualifications make you particularly well-suited for your role in the project that is the subject of the application.”

We suggest limiting this section to one third to one half of a page, dependent on space available (if you have fewer publications and/or grants). The goal of this section is to clearly and concisely describe the qualities that make you best suited to fulfilling your role in the proposed project. Write this in the first person (I am...).

Suggested points to address:

1. Brief (1-3) sentence outline of the proposed project.
2. Describe your outreach, advocacy, community and/or scientific experience highlighting specific skills that are applicable to your leadership in this project. Why is this project feasible because of you?
3. How is your expertise complementary to the expertise of the other members of the team? How does your role integrate into the team structure?
4. Describe your background in directing, coordinating, and supervising projects and programs, and how this makes you well-qualified to lead the proposed work. Give specific examples of the studies you have previously coordinated, highlighting specific experiences applicable to this work demonstrating why you are highly qualified for your role. (For example, if you will be responsible for managing recruitment of participants in the project, describe how you have been successful in this role in other projects.)
5. State what role, if any, you had in generating the preliminary idea for this application.
6. If you have worked with any other members of the team, highlight this as evidence of an existing, productive collaboration.
7. End with a summary (one sentence) that generalizes why your experience has prepared you for this project.

CVs/Resumes (feel free to use what you usually use)

Do not include personal information such as home address in this part. Provide information in the following sections:

1. Education: Institution, Location, Major/Concentration, Degree, and Year.
2. Relevant Experience: Include technical and/or commercial experience. List in reverse chronological order beginning with the current position.
3. Any publications you have authored
4. Other awards or funding.