



Request for Proposals

**Registry/Survey Development Using the Platform for Engaging
Everyone Responsibly (PEER)**

Due:

March 7th, 11:59 PM EST

Deliver To:

Sharon F. Terry, MA

President & CEO

Genetic Alliance

Submissions accepted only by email to: Yulyia Ilchuk (yilchuk@geneticalliance.org)

Registry/Survey Development Using the Platform for Engaging Everyone Responsibly (PEER)

Request for Proposals

Summary:

With this request for proposals (RFP) Genetic Alliance invites organizations, communities, projects, programs, and other collectives interested in health to participate in creating a survey, registry, or campaign using the [Platform for Engaging Everyone Responsibly \(PEER\)](#). PEER enables individuals to share health information on their own terms. This allows trusted communities to collect information, and help advance health for their members while addressing issues that matter to them.

Genetic Alliance will choose sixteen organizations interested in health to utilize PEER to engage their communities in participant-centric research. Ten of these slots will be given to community-based organizations serving marginalized communities, and six slots will be given to disease-related advocacy organizations. These organizations will help Genetic Alliance to assess the experience of PEER sponsors, for the platform's ease of use and also for their participants' reaction to sharing. This project is supported by a grant from the Robert Wood Johnson Foundation (RWJF) and RWJF staff will participate in it and monitor its progress.

Timeline

Request for proposals released: February 8, 2016

Question period: February 8 - February 17, 2016

Questions and answers released: ongoing

Proposals due: March 7 2016 at 11:59 p.m. EST

Applicants notified of decision: March 11, 2016

Question Submission

Please see our current FAQ online at <http://www.geneticalliance.org/white-label>.

Additional questions should be submitted via email to Yuliya Ilchuk,

yilchuk@geneticalliance.org. Please allow two business days for a response. New questions will be posted at <http://www.geneticalliance.org/white-label> on an ongoing basis.

Background

Since 2003, Genetic Alliance has managed a patient-built and -governed, cross-disease research network for participant-centric research on a variety of diseases, known as the Genetic Alliance Registry and BioBank (GARB). Participants in GARB have powered many studies, peer-reviewed papers, clinical trials, and even post-marketing drug studies. In 2008 Genetic Alliance began to expand this vision, working with technology partner Private Access to develop improved ways for individuals to grant faster, easier, and less costly access to otherwise confidential 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 **Platform for Engaging Everybody in Research (PEER)**. PEER is a cross-condition platform with a number of remarkable characteristics. The platform empowers individuals to share health information with each other and researchers on their own terms, by setting sharing, privacy, and data access preferences within a dynamic and granular system made possible by PrivacyLayer® technology from Private Access. This system provides the flexibility needed to engage diverse opinions around data sharing, while creating the opportunity to participate in multiple research projects over time.

PEER launched in 2011, and since then Genetic Alliance has launched 25 registries for a variety of conditions and non-disease communities, all using PEER technology. As the registry expanded, Genetic Alliance identified a need for an improved system, which will permit participating communities and organizations to build registries quickly and efficiently.

The improved PEER system includes a simple dashboard to facilitate easy customization of the system by organizations and collectives wishing to offer it to their communities. This ‘white label’¹ system will be exceedingly easy to set up and deploy. Thirty new organizations will come on to the PEER platform, fifteen of which were selected through competitive award process in early 2015. The next sixteen will be awarded through this RFP in Spring 2016. As a part of winning this award, the organization will participate in assisting Genetic Alliance to improve the experience of set up and deployment.

Purpose: Survey/Registry Development

Genetic Alliance seeks sixteen organizations and/or communities to use the ‘white label’ customization system of the PEER platform to power participant-centric research around health and healthcare, and to engage participants using granular and dynamic consent – a key feature of the platform which puts power and control in individuals’ and communities’ hands.

PEER includes a simple dashboard and accompanying directions to facilitate development of individual organizations’ PEER portals. Using the dashboard and standard operating procedure, organizations and collectives determine the focus of their registry or campaign, design their portal, choose community guides, configure privacy, sharing, and data access options, determine which common data elements² and validated instruments³ to use in portal surveys, and as desired, create new, community-specific questions.

Disease groups, community organizations, and self-organized groups of people (employees of a company, members of a gym or a church) can use PEER to conduct surveys and/or build a registry. An example of PEER deployed for a disease group can be found here:

¹ A **white-label product** or **service** is a product or service produced by one organization (the producer) that other organizations [rebrand](#) to make it appear as if they had made it.

² 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.

³ 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.

<http://www.jsrdf.org/jslife-demo>. We recommend all applicants visit this portal, sign up, and create a profile, and test the system to better understand what it offers.

We are interested in ensuring the sixteen award winners are diverse in multiple ways, including race, ethnicity, socioeconomic status, geography, and that they include traditionally underserved and underrepresented communities. Furthermore, we are looking to test the platform with non-disease centered communities, e.g., public interest, environmental, minority, education, social justice, civic groups etc., that could use health research to prove their goals. We are also interested in non-traditional collectives or affinity groups, e.g., employees of company, gyms, churches or temples, day care centers, clubs, playgroups, prenatal classes, and so on.

Organizations will develop and implement their own PEER 'portals' as part of this project, for a total of sixteen new portals in Phase II of this grant. Each portal represents a mechanism for organizations to engage with communities and power participant-centric research around health or healthcare, either through the creation of a registry or the release of surveys. For each portal:

- Individuals register for an account
- Guides from the community or organization help to inform individuals about privacy choices for low, medium, and high privacy concerns
- Individuals manage their own sharing, privacy, and data access preferences
- Gamified survey questions and longitudinal surveys, which include questions that are specific to the organization and questions that are generalized across the platform, involve participants and keep them engaged
- Individuals are able to share information on one or more conditions or topics, recognizing that many people experience co-morbidities, or have an interest in sharing information on multiple topics

Eligibility

Eligible applicants include:

Any participant-generated, participant-centric, collective: disease advocacy organizations, community organizations, employee organizations, members of a gym, church, temple, neighborhood, or other affinity organization. The collective does not need to have a brick and mortar presence and may be virtual. An individual may not apply unless they lead a group of people and collaborators.

Eligible applicants must have:

- A website (or the sponsoring group can use peerplatform.org to host)
- The capacity to develop survey questions specific to an issue or campaign
- Three individuals (such as leaders in your community) to designate as guides; or use of the standard guides
- The ability to engage their community in a survey including a plan for recruitment, retention, and follow-up for the organization's PEER portal
- The ability to complete and submit the IRB application given Genetic Alliance's template

Genetic Alliance will work directly with award recipients, not through third party organizations.

If you have questions about your eligibility, please contact Yuliya Ilchyk, at yilchyk@geneticalliance.org.

Awards

Genetic Alliance will notify the fifteen organizations that are approved on or before March 11, 2016.

How to Apply

Before submitting your proposal, please email Yuliya Ilchyk (yilchyk@geneticalliance.org) with your intent to submit. This is not binding; we simply need to enlist enough reviewers in advance. 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 PEER portal and their capacity to do so. Proposals must use the attached template, which will ask for the following:

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

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

- Brief description of the organization's or collective's mission
- Brief description of the topic of interest, disease, condition, or campaign on which you wish to focus your PEER portal
- Budget size of your organization, or if not an organization, other indication of your sustainability
- Number of full and part time staff (paid or unpaid) and how they will be supported
- Description of the organization or collective's draft plan to engage community, including goals, target audience, desirable outcomes
- Description of how the organization will increase its reach, support new or existing projects, and improve the experience of setting up PEER over the next 12 months

NOTE: The fees associated with setting up and implementing a PEER portal (\$20,000) will be waived for the participating organizations. Monthly fees associated with maintaining the portal will be waived until September 1, 2016. All portals must be launched on or before May 30, 2016. See table in Appendix B below for further details about monthly fees.

Scoring Criteria	Points
Proposal Clarity	
How clearly does the applicant describe why they should be awarded a PEER portal and registry?	20
Capacity	
Does the applicant demonstrate adequate capacity to successfully complete the project?	20
Impact	
How well does the applicant describe the outcomes they believe a PEER portal will afford them?	10
How novel and/or diverse are the potential participants?	10
Engagement	
How well does the proposal describe the organization and/or initiative's engagement plan?	10
Sustainability	
Does the organization and/or initiative describe a reasonable plan for launching the portal before May 30, 2016?	20
Does the organization and/or initiative describe a reasonable plan for continuing after May 30, 2016?	10
Total	100

The deadline for receipt of full proposals is 11:59 p.m. EST on March 7th, 2016.

Evaluation Criteria

A team of reviewers (from current PEER users and other community participatory research based research advocates) will be appointed for the review process. Reviewers will evaluate the narrative content of each application based on the scoring system outlined above. Genetic Alliance will make the final award decisions based on the application scores as determined by the composite score of the reviewers, the readiness of the applicant organization, geographic distribution of the organizations, and diversity and attention to underserved communities. RWJF staff may be consulted in the process as well.

Genetic Alliance 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 Yuliya Ilchuk, yilchuk@geneticalliance.org.

Inquiries and Additional Information:

Yulia Ilchuk

Email: yilchuk@geneticalliance.org

Website for information about the proposal: <http://www.geneticalliance.org/white-label>

Website for information about PEER: <http://www.geneticalliance.org/peer>

Appendix A: Biographical Sketches

BIOGRAPHICAL SKETCH

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME	POSITION TITLE		
eRA COMMONS USER NAME			
EDUCATION/TRAINING <i>(Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training.)</i>			
INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY

A. 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:

- Brief (1-3) sentence outline of the proposed project.
- 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?
- How is your expertise complementary to the expertise of the other members of the team? How does your role integrate into the team structure?
- 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 experience 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.)
- State what role, if any, you had in generating the preliminary idea for this application.
- If you have worked with any other members of the team, highlight this as evidence of an existing, productive collaboration.
- End with a summary (one sentence) that generalizes why your experience has prepared you for this project.

B. Positions

xxxx-xxxx Name of Position

Honors (selected)

xxxx-xxxx Name of award

C. Selected peer-reviewed publications (Selected from **XX** peer-reviewed publications)

Submit a list of selected peer-reviewed publications or manuscripts, or community publications, in press. Choose no more than 15. Do not include manuscripts submitted or in preparation.

We suggest using the format found below, which is taken from the NIH's example biosketch. Include your five publications that are most *relevant to this application*. Underneath, include ten additional recent publications of importance to the field. Both sections should be presented in chronological order. * When selecting which publications to include, consider the three things that reviewers will scrutinize:

- 1) have you been productive in the recent past?
- 2) what is the quality of the publications selected?
- 3) are the selected publications relevant to what you have been recruited to do in the proposed project?

Most relevant to the current application (in chronological order)

- 1.
- 2.
- 3.
- 4.
- 5.

Additional recent publications of importance to the field (in chronological order)

- 6.
- 7.
- 8.
- 9.
- 10.
- 11.
- 12.
- 13.
- 14.
- 15.

D. Research Support

CURRENT

Grant number	PI Name (PI)	xx/xx/xxxx-xx/xx/xxxx
Title of Grant		
Description of Grant		
Your role		

COMPLETED (last three years)

Grant number	PI Name (PI)	xx/xx/xxxx-xx/xx/xxxx
Title of Grant		
Description of Grant		
Your role		

Appendix B

Ongoing Monthly Fees (to start three months after portal launch)

Such Ongoing Base User Fee will be charged on the first day of the month at the pricing tier based on the number of Participants as of the 20th day of the previous month. You must cancel your use of the Services prior to the next month in order to avoid these additional fees. Otherwise the pricing tiers will automatically renew each month. Up to a maximum of the Financial Means Limit (defined below), the pricing tiers are shown in the table below:

Ongoing Base User Fee Table

Number of Participants	Monthly Fee	Authorized User Seats	Minimum Storage Capacity	Usage of PrivacyLayer®
Up to 100	\$0	3	200 GB	Unlimited
101 - 250	\$150	5	500 GB	Unlimited
251 - 1,000	\$450	10	1000 GB	Unlimited
1,001 - 5,000	\$1,500	15	2.5 TB	Unlimited
5,001 - 10,000	\$2,500	20	5 TB	Unlimited
10,001 - 25,000	\$5,000	35	10 TB	Unlimited
25,001 - 100,000	\$15,000	50	25 TB	Unlimited
100,001 - 250,000	\$25,000	100	50 TB	Unlimited
Over 250,000	Negotiated	Negotiated	Negotiated	Negotiated

To avoid the possibility that our pricing tiers will create a financial burden on smaller or thinly funded organizations and startup initiatives tackling challenges affecting lots of individuals, we will limit our monthly fee to the Financial Means Limit (as hereinafter defined). In the event the monthly fee based on the standard tier pricing (see the above table) exceeds the Financial Means Limit, then upon your written request accompanied by appropriate documentation, we will reduce your monthly fee to an amount equal to one-twelfth (1/12th) of 2.4% times your total operating cost for the previous year, or \$200/month (*i.e.*, one-twelfth of \$2,400 per year), whichever is greater (the “Financial Means Limit”). For example, if your organization had total operating costs last year of \$200,000, you would pay us *no more than* \$400/month as your monthly fee no matter how many Participants you enroll in the PEER registry.