Platform for Engaging Everyone Responsibly (PEER)
We begin with a novel perspective about who controls access to data...

Privacy and access in perfect balance
Your solution for online privacy and access to confidential information.*

Registries can be*...  
* And commonly are
- Physician-centric
- Condition-centric
- Investigator-centric
- Organization-centric
- Institution-centric
- Inquiry-centric
- Sponsor-centric
- Data type-centric
- Study-centric
- Network-centric
- Organ or body part-centric
- Participant-centric*

But we decided to try something totally new... bold, paradigm-shifting, and create a registry that is (that truly is)

* And not just in name only
PEER’s architecture is different than a typical registry

The core components of a typical registry consist of functionality for data entry, a database of de-identified data, and facility for inquiry and/or analysis of that data based on the privacy and access policy of the registry owner to which all participants must consent in advance. Contact information for individual subjects – if available – are most often loosely coupled, and outside the registry.
PEER’s architecture is different than a typical registry

In order to be participant-centric, PEER has added a number of functions to the data entry facility and new privacy controls from Private Access that empower participants to create and manage access to all of their information. We’re able to move the contact details into the registry, with the right to access this data being separately managed by each participant.

Core components of the PEER system

- **Data Entry Facility**: Survey questionnaire, contact information, guide-based assistance, mobile interface, security and registration
- **PrivacyLayer®**: To create and manage permissions for sharing patient data wherever that data resides and at any level of granularity
- **Data Query Facility**: Search index, privacy-based ontology, simple and advanced search, alerts, access requests, security and registration
- **Health Data**: De-identified data patient reported
- **Contact Info.**: Personally identifying info
- **Privacy Directives**: Set by patient, dynamic & easy
- **Permissible Information**: From search and search alerts

*Privacy and access policy reflecting the goal of PEER being participant-centric.*
This is the first time that everyone, regardless of health or disease state, can contribute their health information, get instant feedback on how they compare to others, and still be in control of who sees and uses their information...

PEER is the technology behind TrialsFinder, Reg4ALL, Free the Data and 7 sites for the PDUFA V Patient-Focus Drug Development initiative.
Because people have vastly different views about privacy

Virtually every article on Big Data, every policy body, every medical research project is looking for a solution to the question: “How can we share the clinical and genetic data of millions of individuals and still respect their diverse wishes?”

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**Public Views on Privacy and Health Research**

Study commissioned by Institute of Medicine (2009)

and conducted by Dr. Alan F. Westin

- 1.5%: Okay for researchers to use my data without my consent at all...
- 10%: Willing to give general consent in advance for use of my data without being contacted...
- 24%: Consent is not needed if my identity will never be revealed and the study is IRB supervised...
- 48%: I would not want researchers to contact me or to use my data under any circumstance...
- 16.5%: Want each study seeking to use my data to contact me in advance and to get my specific consent each time...

*Percentages shown reflect the views of those persons expressing an opinion. An additional 20% of the persons surveyed indicated that they were “Not sure.”*
PEER enables a range of granular access controls, with ease

Participants use access controls to specify who can, and cannot, access or use their data, and for what purpose.

“Contact Information” And separately, who can have access to their contact information.

“Use” And who can use or export data from the PEER system.

“Discovery” Each participant controls who can locate their de-identified data...

For multiple categories of uses, and specified usage rights...

And given the option to Permit, Decline, or wait for more information before deciding...

And the opportunity to change these preferences over time.

This can include:
- Bridge
- Personal Genome Project
- PatientsLikeMe, and so on.

1 So long as the data is in PEER or a system that adheres to the person’s Private Access settings.
With a highly intuitive guide structure, notifications & dynamic consent

Participants can draw support from knowledgeable members of their community about considerations regarding data sharing and access controls...

...and do this for each member of their family, or use an existing group of settings as the basis for others...

And with an easily accessible audit log for all activity being maintained at all times...

With dynamic consent from a computer or a smartphone...

...or set their preferences manually, without influence by anyone...
With an engaging interface for questions and sponsorship opportunities

Questions appear in a pleasing user interface, and provide immediate feedback on how others responded to the same question...

And to review their prior answers, make updates and/or remove the data at any time.

Organizational sponsors have an opportunity to earn revenue from informative or inspirational ads by key constituents, or to suppress these messages.
Extending PEER’s to being cross-disease and cross-organizational

In order to fulfill the goal of being cross-disease and cross-organizational, we’ve added other tools for customization of the front-end portal and the researcher portal, including selection of guides and curation of questions, and a number of administrative tools for patient support groups and other host organizations.

Privacy and access policy reflecting the goal of PEER being participant-centric

PrivacyLayer®
To create and manage permissions for sharing patient data wherever that data resides and at any level of granularity

Permissible Information
From search and search alerts

Core components of the PEER system

Patient Portal
- Customizable for patient population
- “Gamified” survey questions
- Health profile
- Privacy preferences
- Guides to assist
- Dynamic consent
- Audit trail

Data Entry Facility
Survey questionnaire, contact information, guide-based assistance, mobile interface, security and registration

Data Query Facility
Search index, privacy-based ontology, simple and advanced search, alerts, access requests, security and registration

Contact Info.
Personally identifying info

Health Data
De-identified data patient reported

Privacy Directives
Set by patient, dynamic & easy

Researcher Portal
- Search engine that respects patients privacy wishes
- Custom search alerts
- Bookmarks
- Do not show again
- Future (query from EHR data)

http://tinyurl.com/m7klhls
With an ability to embed the PEER platform directly into any website

- Your selected logo art and call-to-action headline appears with fonts, background colors and links that follow your theme
- The opportunity to substitute your leadership and key trusted members of your community
- PEER network’s unique participant-centric Privacy Policy and Terms of Use automatically extend to use on your site and are easily accessible, including seal certificates Web users trust
- The PEER widget appears in an iFrame that you place directly on your webpage
Each sponsor creates & manages from a single dashboard

Select and edit each element in the PEER widget to appear in the theme of your website...

...and see a live preview of your page as you do

Curate inquiries (content, sequence, dependencies, etc) from a starting point of over 22,000 questions

Create referral codes to use on your printed communications...

...and view statistics for how all of these assets perform and why

Also create custom badges to display on other websites

…and data to which you have rights can be located and downloaded in CSV format for analysis

Code is simply placed into page source and it begins working instantly
Contact Information

To learn more about PEER:

Webinar series on PEER: [www.geneticalliance.org/webinars.reg4all](http://www.geneticalliance.org/webinars.reg4all)

Webinar on Genetic Alliance Registry and BioBank: [www.youtube.com/watch?v=1VKEYbywejU&feature=youtu.be](http://www.youtube.com/watch?v=1VKEYbywejU&feature=youtu.be)

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