

## Frequently Asked Questions about research at PatientsLikeMe

One of our objectives at PatientsLikeMe is to accelerate the pace of medical research through the use of our unique platform. We are always interested to hear from patients, healthcare professionals, academic researchers, companies, and non-profit organizations about ideas they have for research.

Our dedicated Research and Development (R&D) team is tasked with developing the features of the website, designing new communities, maintaining the quality of our data, and carrying out analytic work for our clients. In addition we also carry out scientific research, and as a very small company we are proud of [the research output](#) created both internally and in collaboration with our partners.

To help potential collaborators we have assembled responses to some frequently asked questions:

### **General questions:**

#### **Q: What kind of research do you do?**

A: Our research team come from a diverse array of backgrounds including patient reported outcomes, drug discovery, human computer interaction, predictive modelling, health behaviour, sociology, neuropsychology, nursing and genetics. In addition to our ongoing work to improve and expand the site, we publish research findings about our disease communities in peer-reviewed journals and at international conferences, more of which you can read about on [our research page](#).

#### **Q: How can I join your team?**

A: Please see [our careers page](#) for more guidance

#### **Q: How good is your data and where does it come from?**

A: All the data we use right now is self-reported and comes from patients and their caregivers. Primary outcome measures consist of existing high quality self-reported patient outcome measures where available; otherwise we develop our own tools through a rigorous psychometric development process. Where there are objective markers (such as CD4 count in HIV) we use those in combination with our symptom rating system, which asks patients to endorse symptoms as none/mild/moderate/severe.

#### **Q: Have you thought of doing research on the relationship between environmental exposures and diseases (e.g. chemical exposure, occupation, infection)?**

A: While this is an interesting research area the reality is that it is very difficult to do well. This is on our long-term plan and we would be willing to consider any funded proposals in this area with a strong chance of being able to produce meaningful conclusions.

**Commercial research questions:****Q: I'd like to recruit some patients for a focus group or survey for a commercial enterprise, who should I contact?**

A: Please send a message to [our partnership team](#) with an outline of the patients you'd like to contact and for what purpose. If you are an agency representing a pharmaceutical or medical device company we'd also be grateful if you could let us know who the client is. We'll then get back to you to discuss whether your request is suitable for our community, pricing structure, and suggestions for the best way to maximize your budget. Please do not post in our forum or contact patients directly without an agreement in place, as this is a violation of our terms of service.

**Q: I have a research project I'd like to do in a disease, but you don't have a community for that condition yet.**

A: Ultimately we want to have a community for every life-changing illness that exists, but each new disease we tackle introduces new challenges and may require developing new web functionality to optimize the value of the community for its users. The process of developing a disease community involves significant resources to meet the quality standards we are committed to maintaining and therefore requires funding. If you're interested in working with us to develop a community for a new condition we don't have yet, please get in touch with us at [our partnership team](#). We'd be happy to discuss how you could benefit from preferential access to data from that community, as well as the opportunity to benefit thousands of patients who want to improve their health outcomes through sharing.

**Non-Commercial / Academic research questions:****Q: I'm a student and I'd like to post a link on your site to my survey for a research project, is that OK?**

A: Because we want to minimize response burden to our users and avoid duplication of work we don't typically allow links to student projects from our site. Please do not post in our forum or contact patients directly without an agreement in place, as this is a violation of our terms of service. If you have a project you want to discuss, reach out to our [research team](#).

**Q: I am a clinician / researcher and would like to collaborate with you on a new research project. Who should I contact?**

A: We are proud to collaborate with some of the leading research institutions in the world on useful and interesting academic research. Please write to [the research team](#) with your initial research proposal. If we think a research project has the potential to benefit our users we would be happy to assist you in writing a grant proposal and helping to describe what we do for your local Internal Review Board (IRB). The proportion of funding we would receive depends on a number of factors including the contribution of our staff to the design, the difficulty of accessing the specific population of interest, and the source of funding.

**Q: I am a clinician / researcher and would like your help referring participants from your site to an ongoing study I am running.**

A: We have significant experience of referring patients to academic clinical trials and research studies, with excellent referral rates. Through our unique dataset we are able to specifically target subpopulations such as newly diagnosed patients or only those that live near your research sites, and we monitor new patients that register on the site to contact them where they meet your criteria. Please email [the research team](#) with your study protocol (including number of patients required, inclusion/exclusion criteria) and details of your available funding and we will get back to you with a recommended price structure and plan to help you recruit the participants you need on time and under budget. Please note that we do not have a patient referral service that is free of charge.

**Q: I'm writing a paper about PatientsLikeMe and would like to cite some sources about you. How should I proceed?**

A: In addition to our [research page](#) and the [research section of our blog](#) you might like to try [Google Scholar](#) to read some examples of studies that have referred to us. We ask that you please [send us a note](#) to let us know about the citation once your study is published. To arrange to speak with one of our research scientists for your paper, please contact [our media relations team](#).

**Q: I am a Journal Editor or grant funder and need a peer-reviewer for an article or grant that refers to your website or Health 2.0. Who do I contact?**

A: Our [research team](#) have a variety of experiences in different fields from genetics to sociology. Please [contact our R&D Director, Paul Wicks PhD](#), for suggestions of the best member of our R&D team to act as a peer reviewer.

**About PatientsLikeMe**

PatientsLikeMe ([www.patientslikeme.com](http://www.patientslikeme.com)) is the leading online health community for patients with life-changing conditions. PatientsLikeMe creates new knowledge by charting the real-world course of disease through the shared experiences of patients with ALS, multiple sclerosis, Parkinson's, HIV, and mood conditions (including depression, bipolar, anxiety, OCD and PTSD) and fibromyalgia. While patients interact to help improve their outcomes, the data they provide helps researchers learn how these diseases act in the real world. PatientsLikeMe endeavors to create the largest repository of real-world disease information to help accelerate the discovery of new, more effective treatments.