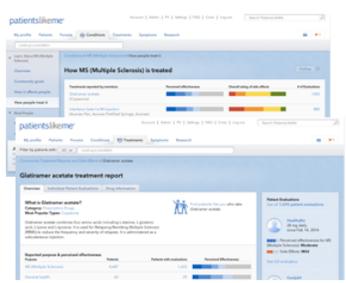
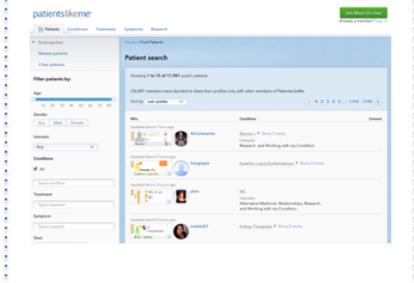
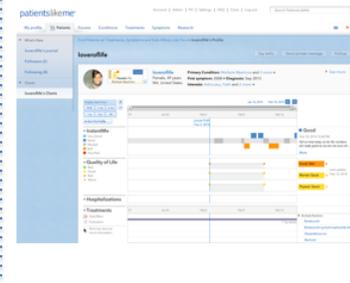


Research Collaborations with PLM PATIENTS Grant

This brief guide to PatientsLikeMe provides an overview of key considerations in determining project feasibility.

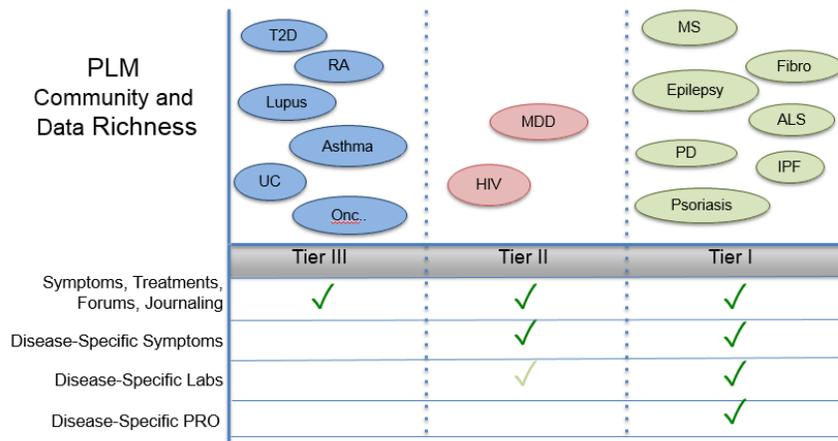
Why do patients use PLM?

<h4>Learn</h4> <p>about living with and treating life-changing conditions</p>	<h4>Connect</h4> <p>with others sharing those experiences</p>	<h4>Track</h4> <p>their history and progress over time</p>
		
<ul style="list-style-type: none"> • Answer the question “Is this normal?” • Learn from aggregated patient treatment and symptom data 	<ul style="list-style-type: none"> • Search patients based on age, gender, disease, treatment, symptoms, interests, etc. • Day-to-day support • Live better, together 	<ul style="list-style-type: none"> • Document changes to symptoms and new treatments, triggers and side effects • Generate a real-world outcomes research data

In which diseases are PLM’s most extensive datasets?

Tier 1 communities have the largest patient numbers and the most data.

Three tiers of disease communities, with varying levels of feature sophistication, have been created through client-driven projects and investment.



What kinds of data are available through PLM?

Profile data

Structured data
 Unstructured data – e.g., comments on forums
 Web-logs – e.g. clicks, time on site

Survey data

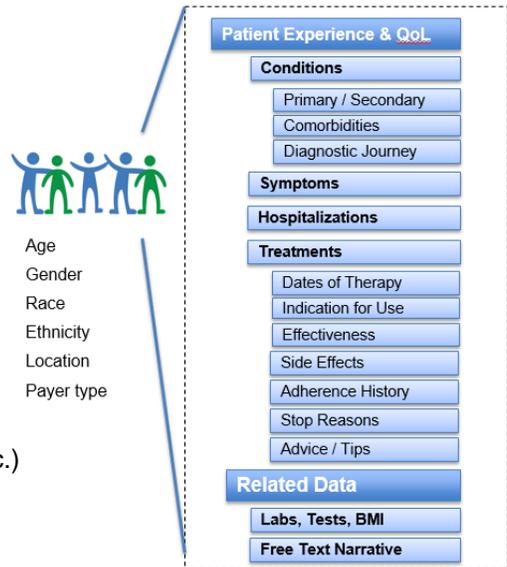
(supplementary data collection of data not available on PLM platform)

Open text
 Multiple choice
 Profile data pull-through (basic info)

Specialized Projects

Patient Reported Outcomes Measurement development
 Wearables projects (activity trackers, sleep monitors, etc.)
 Patient informed clinical trials projects

Patient Reporters PatientsLikeMe Data Fields



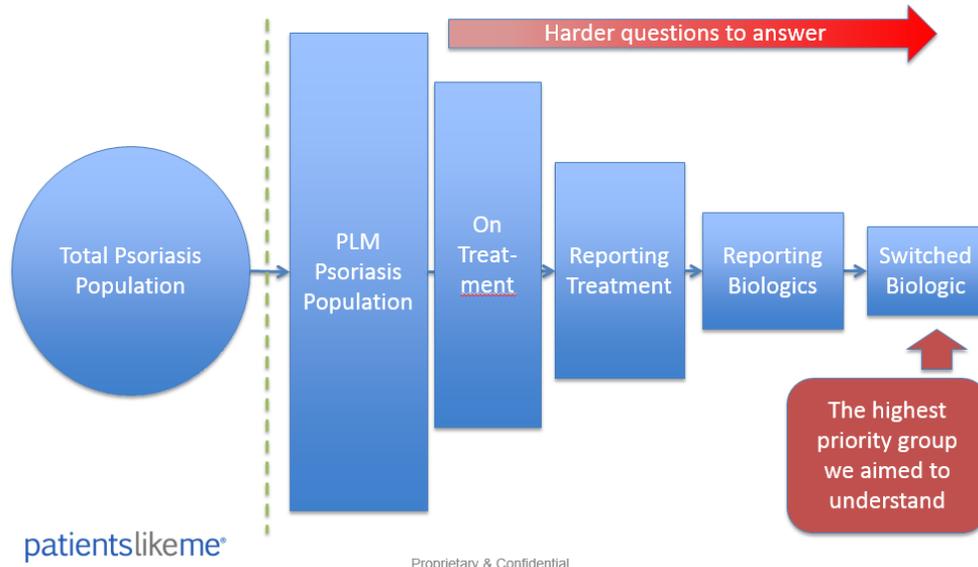
Which diseases have available outcome data?

- **Multiple Sclerosis** - Multiple Sclerosis Rating Scale (MSRS)
- **Pulmonary Fibrosis** - Pulmonary Fibrosis Severity Score
- **Fibromyalgia / Chronic Fatigue Syndrome** - Pain and Fatigue Rating Scale (PFRS)
- **Epilepsy** - Seizure Survey
- **ALS** - Functional Rating Scale (FRS)
- **Parkinson’s Disease** - Parkinson’s Disease Rating Scale (PDRS)
- **Psoriasis** - Dermatology Quality of Life Index (DLQI)
- **Multiple System Atrophies, Progressive Supranuclear Palsy** - Movement Disorder Rating Scale
- **Autism Spectrum Disorder** - Autism Treatment Evaluation Checklist (ATEC)
- **Neuromyelitis Optica** - Neuromyelitis Optica Rating Scale (NMORS)

What factors do we consider in determining project feasibility?

- » **Community tier** – data rich communities are easier to research
- » **Recent patient activity** – the greater the recent patient activity, the higher the potential sample
- » **Cross-sectional vs longitudinal research** – longitudinal research increases effort, messaging, and cost
- » **Regions required (US vs non-US)** – limiting region reduces sample size
- » **Timeline** – shorter timelines increase cost
- » **Sample size** – pre-determined sample sizes may or may not be achieved depending on other factors
- » **Funding required to recruit new patients** – this can add greatly to expense, depending on the difficulty of reaching the target population
- » **Funnel point (see below)** - Depending on the specificity your inclusion criteria, we may or may not be able to field a large enough sample. This example with psoriasis shows how available subgroups can dwindle rapidly with increasingly stringent inclusion criteria.

A narrowing funnel between sample and interest



What is the approximate budget required?

PLM's suggested approach is to inquire on a per-project basis to determine a budget estimate, recognizing that we cannot justify engaging on an annual budget of less than \$50K in direct costs.

PLM also suggests knowing the requirements of the study, including anticipated methods, sample size, stratification analyses, and timeline to completion.

In general, PLM prefers to be involved in the creation of any questionnaires to be fielded to our members. Our communications, survey tools, and analyses are optimized for our unique platform and the data it can generate. We are more than happy to collaborate on methodology, question creation, and analysis planning.

Who do I contact to discuss collaborations with PatientsLikeMe?

Send a brief description of your proposed research (1-2 paragraphs) with the subject line "*Proposed Collaboration with PatientsLikeMe*" to the PATIENTS Program (patients@rx.umaryland.edu).