PATIENT-LED
RESEARCH
COLLABORATIVE

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Working with the Patient-Led Research Collaborative

For Health-Tech Organizations

Hi, thank you for getting in touch with Patient-Led Research. We are grateful that you are interested in partnering with us! Before we meet with your team, we would like to provide some context and conditions we have for collaboration. Our end goal is to create aligned partnerships with organizations that can grow alongside our patient-led movement.

Our Values and Conditions for Collaboration

- Your platform prioritizes **data privacy**. Any use of our patient data beyond the study collected for will require patient consent.
- Accessibility and patient-informed user experience. **We are a team that respects people's time and mental capacity as they navigate Long COVID**. We would like to collaborate with teams who are familiar with methodologies of participatory design.
- You have **a live demo** of your system/tool/product, and can **provide us with account access to your platform** for us to look around. Due to the urgency of Long COVID, we are looking for collaboration with teams that have a proven track record of building solutions that serve similar patient needs.

About Our Patients' Needs

- Long COVID patients need access to data to help them advocate for their condition and get access to quality care. These can be documents they provide to primary physicians, ER, specialists, etc

- Our patients face disbelief from doctors about their prolonged sickness and unexplained symptoms
- Currently, our patients do not need a new platform/forum for community support and activism. We have existing support groups that are well run/managed on platforms that our patients are familiar with

Short-Medium Infrastructure Needs

Automate patients' access to their survey results in a secure, mobile friendly format HIGH PRIORITY SHORT TERM

  - Platform needs to support importing (partial) survey responses in bulk and individually
  - Display should be mobile-friendly. Patients use their self-reported survey responses in different healthcare contexts
  - Data must be easy to export. Patients sometimes records to take to the ER or bring along to a new health care provider to advocate for belief and treatment

Straightforward access to study results HIGH PRIORITY SHORT-MEDIUM TERM

  - Patients to have access to our initial analysis as an advocacy resource, including a symptom list relevant to Long COVID (this has been widely asked for)
  - Easy to understand data visualizations. Patients can drill down data to country/community and view comparisons with population for applicable data-points

Centralize data sharing touchpoints HIGH PRIORITY MEDIUM TERM

  - We would like to give patients ability to accept or reject consent for other research teams we partner with
  - Dashboard for research team to manage data sharing requests, scope of data sharing, and to track their usage of this data (eg. date of exports)

Centralize patient-researcher communication touchpoints MEDIUM TERM

  - We would like to move to an organized system that allows us to keep track of issues that participants have during studies
  - We currently help our participants through various communication channels: emails, tweets, slack. This gets overwhelming and redundant for the team as we scale

Democratic system for patients to have a say on analysis and further research LONG TERM

  - Patients care about different areas of a study that pertain to their symptoms
  - We envision a voting mechanism which we can distribute to participants to get their feedback