Beyond Embargos: Accessibility Considerations for Building New Public Access Policies

Lisa McCorkell, MPP
Co-Founder, Patient-Led Research Collaborative

PATIENT-LED
RESEARCH
COLLABORATIVE

Disclosures

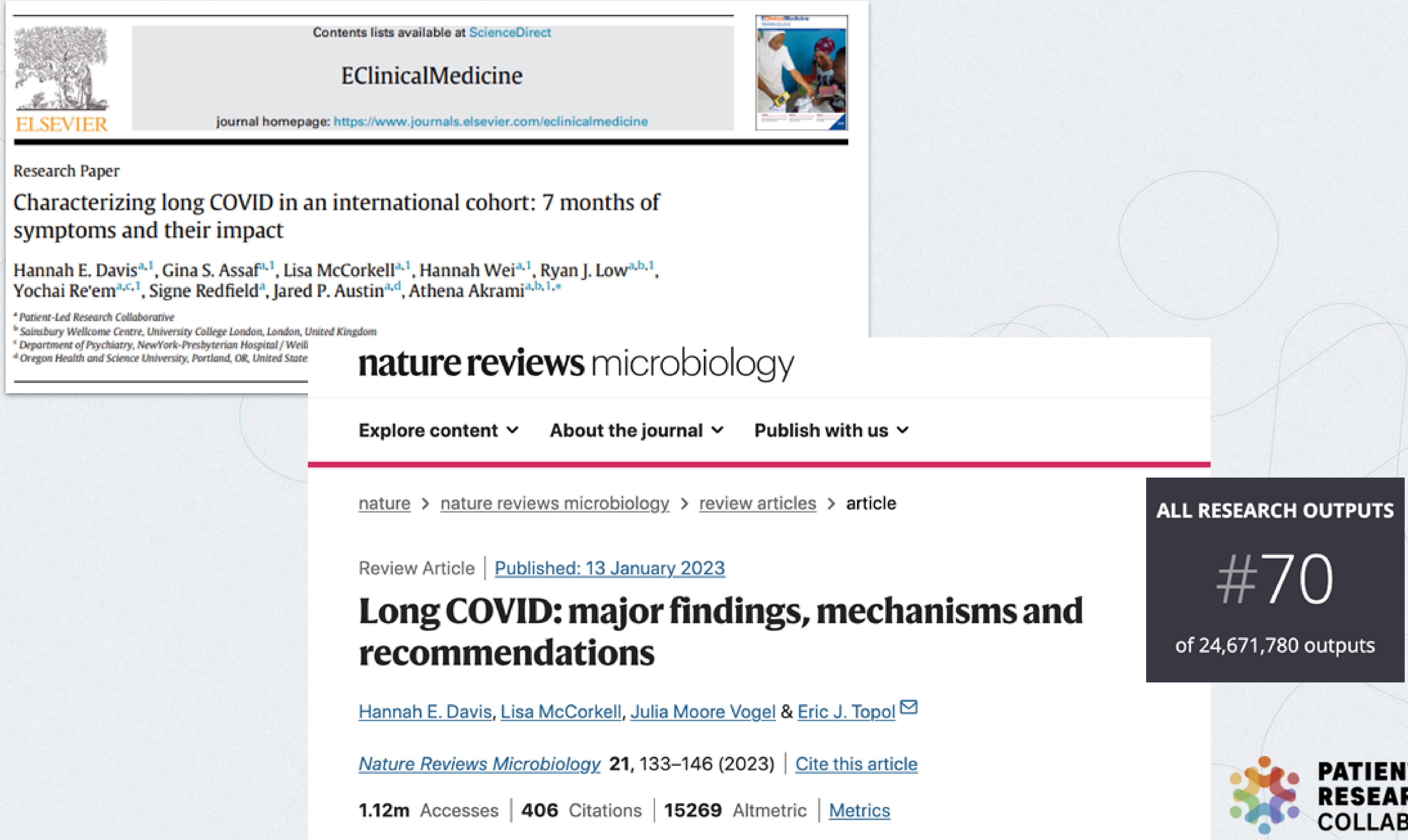
No relevant disclosures to report

PATIENT-LED
RESEARCH
COLLABORATIVE

Who is PLRC?

- Team of people with Long COVID and associated conditions, led by 4 women, now 50+ members over 4 continents
- Multidisciplinary backgrounds:
  - Survey design & participatory design
  - Qualitative research
  - Public policy
  - Research engineering
  - Data science & machine learning
  - Health activism
  - Medicine, medical research (NY Presbyterian/Weill Cornell Medicine)
  - Neuroscience (University College London)
- Formed out of the Body Politic COVID Support Group (on Slack) in April 2020
- Conducted the first research on Long COVID in May 2020
- Have continued to do our own research, fund research, consult/partner on research, give feedback on research/guidelines/policy, push field of patient-led research forward, and advocate for better policies

PATIENT-LED
RESEARCH
COLLABORATIVE



Contents lists available at ScienceDirect

EClinicalMedicine

journal homepage: https://www.journals.elsevier.com/eclinicalmedicine

Research Paper

Characterizing long COVID in an international cohort: 7 months of symptoms and their impact

Hannah E. Davis[a,1], Gina S. Assaf[a,1], Lisa McCorkell[a,1], Hannah Wei[a,1], Ryan J. Low[a,b,1], Yochai Re'em[a,c,1], Signe Redfield[a], Jared P. Austin[a,d], Athena Akrami[a,b,1,*]

[a] Patient-Led Research Collaborative
[b] Sainsbury Wellcome Centre, University College London, London, United Kingdom
[c] Department of Psychiatry, NewYork-Presbyterian Hospital / Weil
[d] Oregon Health and Science University, Portland, OR, United State

---

nature reviews microbiology

Review Article | Published: 13 January 2023

Long COVID: major findings, mechanisms and recommendations

Hannah E. Davis, Lisa McCorkell, Julia Moore Vogel & Eric J. Topol

Nature Reviews Microbiology **21**, 133–146 (2023) | Cite this article

1.12m Accesses | **406** Citations | **15269** Altmetric | Metrics

ALL RESEARCH OUTPUTS

#70

of 24,671,780 outputs

PATIENT-LED
RESEARCH
COLLABORATIVE

Barriers to Accessing and Understanding Research Results

- Cost
- Time and energy intensive to search and read; cognitively taxing
- Understandability
  - Technical jargon
  - Often need a background in statistics/research
- Lacking context
- Implications of research not clearly stated
- Discussion about research not included
- Searchability
- Accessibility
  - Generally requires internet access
  - May not meet WCAG standards
  - Audio options
- Slow pace

Implications of Barriers

- The communities that research is about may not have access to research results about their own lives or even research they participated in.
    - Access decreases with lower socioeconomic status, education level, and internet access, exacerbating existing inequities
- Marginalized communities kept out of academia and doing their own research
- Leads to worse health outcomes
    - Patients and caregivers have less agency over health decision-making
    - Patients and caregivers not up-to-date on latest research
    - Patients and caregivers not as able to help inform healthcare providers on new research and what treatments to explore
    - Patients and caregivers are not as able to advocate for themselves
    - Patients and caregivers are not as able to contribute to/lead research

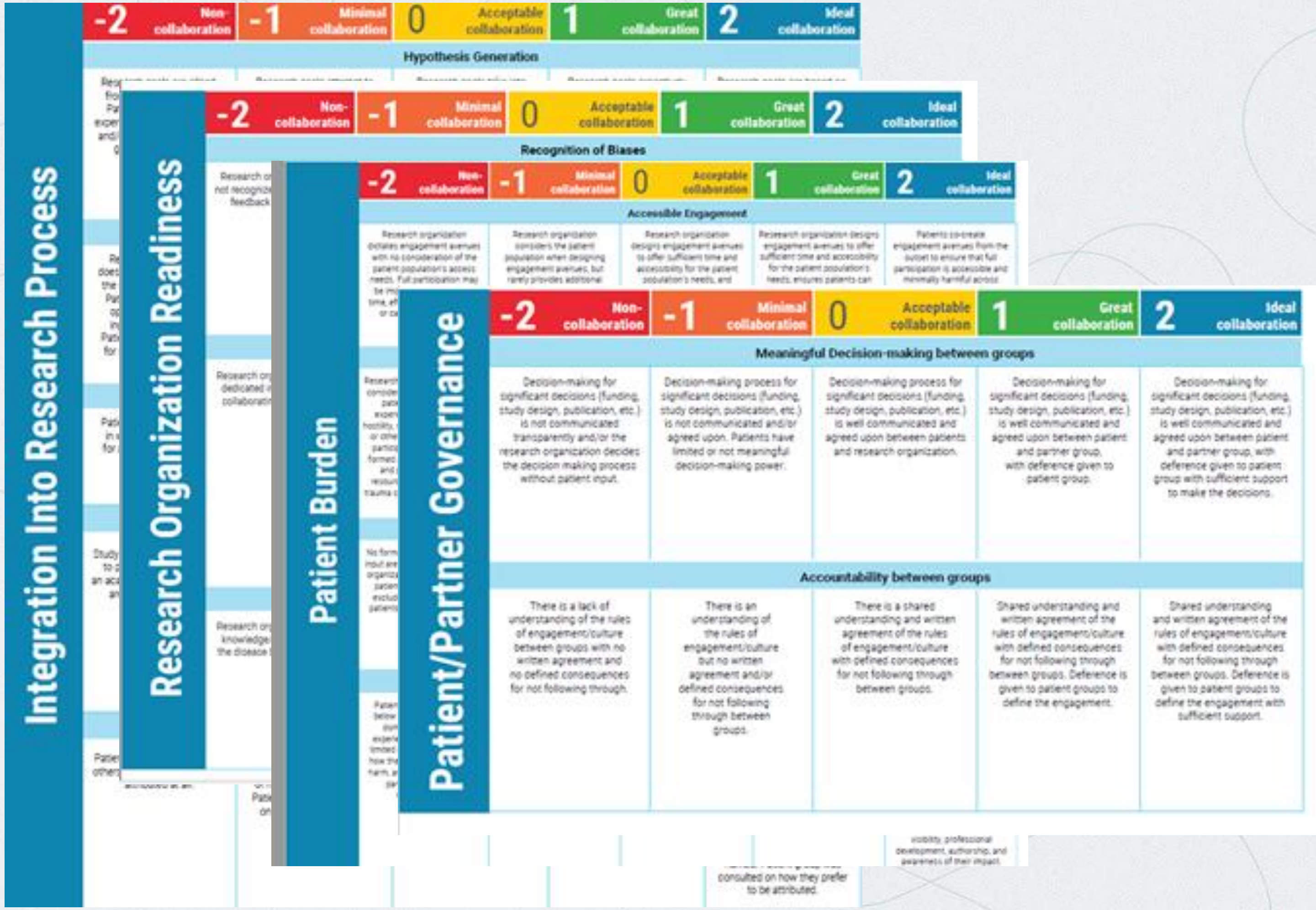
What does true access to research results mean?

To be able to:

- Read it
- Understand it
- Use it
- Share it
- Be part of it

All without causing harm

Patient-Led Research Scorecards



Integration Into Research Process

Hypothesis Generation

Research Organization Readiness

Recognition of Biases

Patient Burden

Accessible Engagement

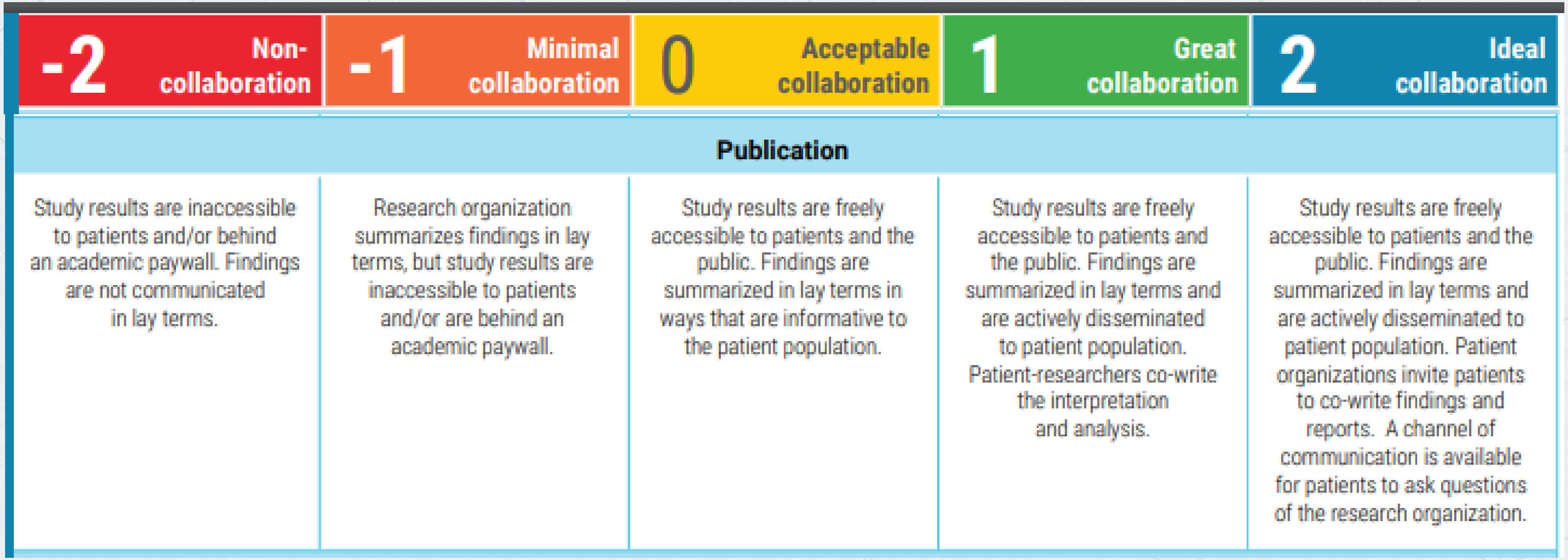
Patient/Partner Governance

-2 Non-collaboration	-1 Minimal collaboration	0 Acceptable collaboration	1 Great collaboration	2 Ideal collaboration
Meaningful Decision-making between groups				
Decision-making for significant decisions (funding, study design, publication, etc.) is not communicated transparently and/or the research organization decides the decision making process without patient input.	Decision-making process for significant decisions (funding, study design, publication, etc.) is not communicated and/or agreed upon. Patients have limited or not meaningful decision-making power.	Decision-making process for significant decisions (funding, study design, publication, etc.) is well communicated and agreed upon between patients and research organization.	Decision-making for significant decisions (funding, study design, publication, etc.) is well communicated and agreed upon between patient and partner group, with deference given to patient group.	Decision-making for significant decisions (funding, study design, publication, etc.) is well communicated and agreed upon between patient and partner group, with deference given to patient group with sufficient support to make the decisions.
Accountability between groups				
There is a lack of understanding of the rules of engagement/culture between groups with no written agreement and no defined consequences for not following through.	There is an understanding of the rules of engagement/culture but no written agreement and/or defined consequences for not following through between groups.	There is a shared understanding and written agreement of the rules of engagement/culture with defined consequences for not following through between groups.	Shared understanding and written agreement of the rules of engagement/culture with defined consequences for not following through between groups. Deference is given to patient groups to define the engagement.	Shared understanding and written agreement of the rules of engagement/culture with defined consequences for not following through between groups. Deference is given to patient groups to define the engagement with sufficient support.

PATIENT-LED
RESEARCH
COLLABORATIVE

https://cmss.org/patient-led-research-integration/

Integration into the Research Process



-2 Non-collaboration	-1 Minimal collaboration	0 Acceptable collaboration	1 Great collaboration	2 Ideal collaboration
Publication				
Study results are inaccessible to patients and/or behind an academic paywall. Findings are not communicated in lay terms.	Research organization summarizes findings in lay terms, but study results are inaccessible to patients and/or are behind an academic paywall.	Study results are freely accessible to patients and the public. Findings are summarized in lay terms in ways that are informative to the patient population.	Study results are freely accessible to patients and the public. Findings are summarized in lay terms and are actively disseminated to patient population. Patient-researchers co-write the interpretation and analysis.	Study results are freely accessible to patients and the public. Findings are summarized in lay terms and are actively disseminated to patient population. Patient organizations invite patients to co-write findings and reports. A channel of communication is available for patients to ask questions of the research organization.

https://cmss.org/patient-led-research-integration/

PATIENT-LED
RESEARCH
COLLABORATIVE

Recommendations to Ensure Equitable Access to Research Results

- **Free access to all**
- **Develop policies in partnership** with a) the communities the research is intending to serve/study, and b) people with disabilities to ensure the results are accessible
- Require **plain language summaries,** ideally written/reviewed by people in the communities the research is focused on (paid)
    - Question asked/answered, population the question/answer applies to, what the answer/result is
    - Links for further reading, discussion around research, context of research
    - Visuals/infographics
    - Address common questions people in that community will have
- Develop and disseminate guidance on **how to use/digest/search research**
    - For all research studies and content specific
- Require results to be written in a way that **represents the communities it is studying**
    - E.g. Require reporting of results by gender and race/ethnicity using best practices in language and how participants self-identify

PATIENT-LED
RESEARCH
COLLABORATIVE

Recommendations to Ensure Equitable Access to Research Results

- Proactively **disseminate research results to communities** through grant programs/community health workers
- **Aggregate findings** on a central site that is easily searchable (e.g. ME-pedia.org)
- Improve awareness that **libraries can help** with searching and accessing
- **Create UX/UI protocols** to easily highlight/navigate to most important parts of articles
    - Require glossaries of terms and abbreviations that are easy to access
- Ensure documents (PDFs, Word docs, webpages, etc.) are **accessible according to WCAG standards** and require audio versions
- Ensure articles that are **referenced can be accessed** for free, at least with a plain language summary
- Ensure **research participants have access to their own data**
- **Encourage preprints**, including by ensuring publication in journals for manuscripts that have been preprinted

PATIENT-LED RESEARCH COLLABORATIVE

Thank you!

lisa@patientledresearch.com
team@patientledresearch.com

PATIENT-LED
RESEARCH
COLLABORATIVE