PATIENT-LED RESEARCH COLLABORATIVE

Patient-Driven Research Panel

Lisa McCorkell
Co-Founder, Patient-Led Research Collaborative

June 30, 2023

WHO WE ARE

- ➔ Team of people with Long COVID and associated conditions, non-hierarchically led by 4 women, now 45+ 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

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What Does COVID-19 Recovery Actually Look Like?

An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team

Generated from survey data organized by decentralized team of COVID-19 patients, exported on May 2, 2020 (640 Responses)

Report Released: May 11th, 2020 by
https://patientresearchcovid19.com

Report created and written by volunteers from the COVID-19 Body Politic Slack Group including: Gina Assaf, Hannah Davis, Lisa McCorkell, Hannah Wei., O'Neil Brooke, Athena Akrami, Ryan Low, Jared Mercier, and Adetutu A.
Survey Authors and Contributors Include: Gina Assaf., Tina L., Annie C., Monica S., Jared Mercier, Lauren N., Noel H., JD Davids, and Susie.

Assaf, G. et al. What Does COVID-19 Recover Actually Look Like? An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team. https://patientresearchcovid19.com/research/report-1/

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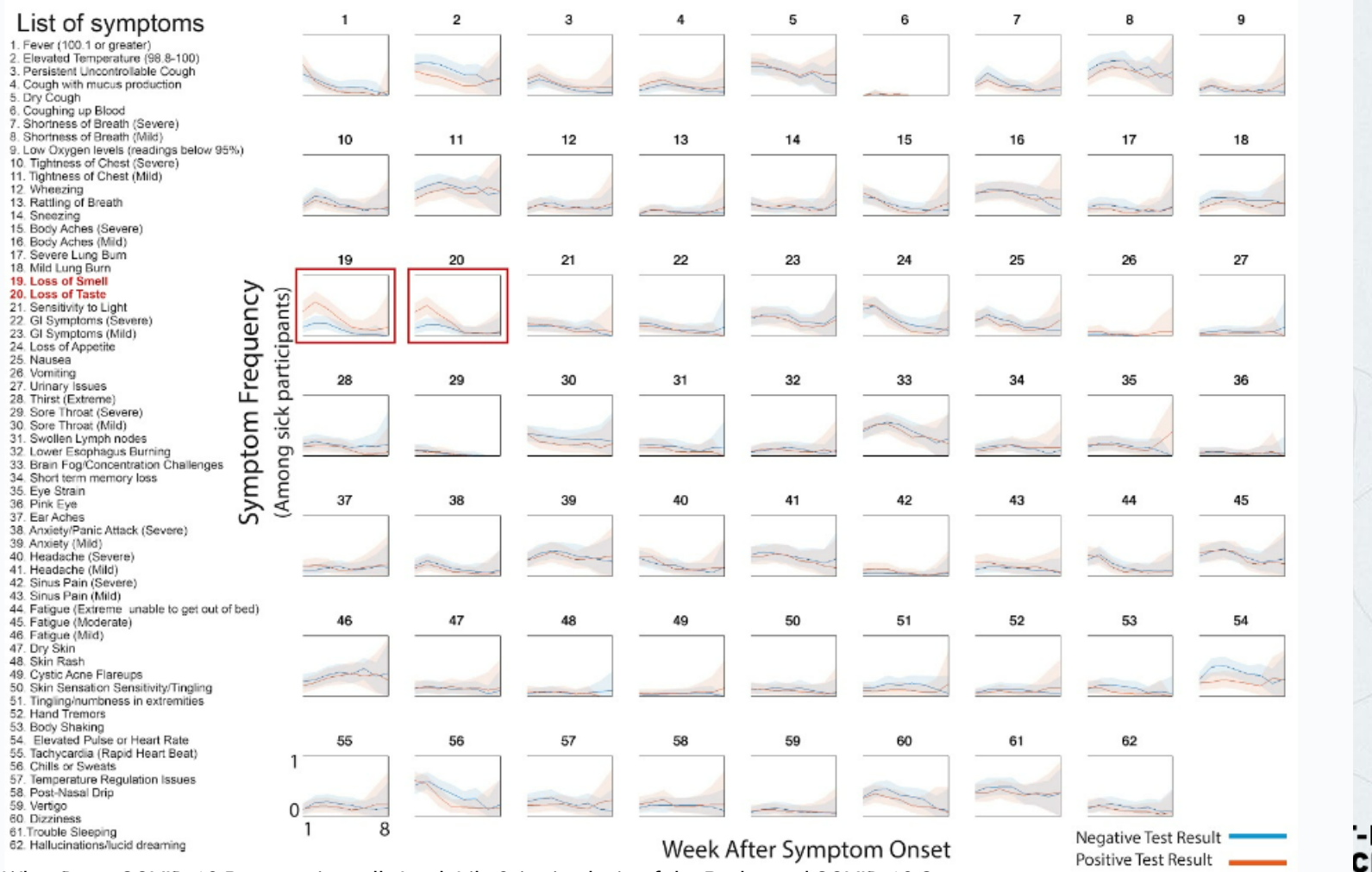

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Contents lists available at ScienceDirect

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 / Weill Cornell Medicine, NYC, United States
[d] Oregon Health and Science University, Portland, OR, United States

Davis, H. E. et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *eClinicalMedicine* 38, 101019 (2021). https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext

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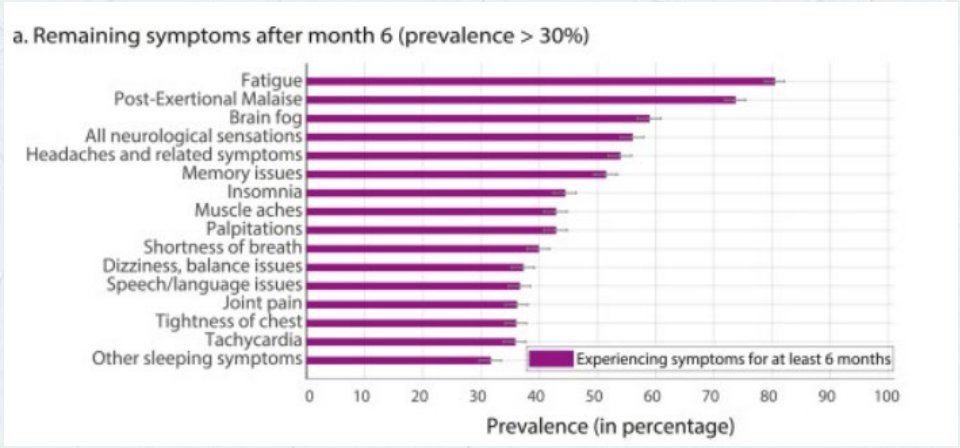

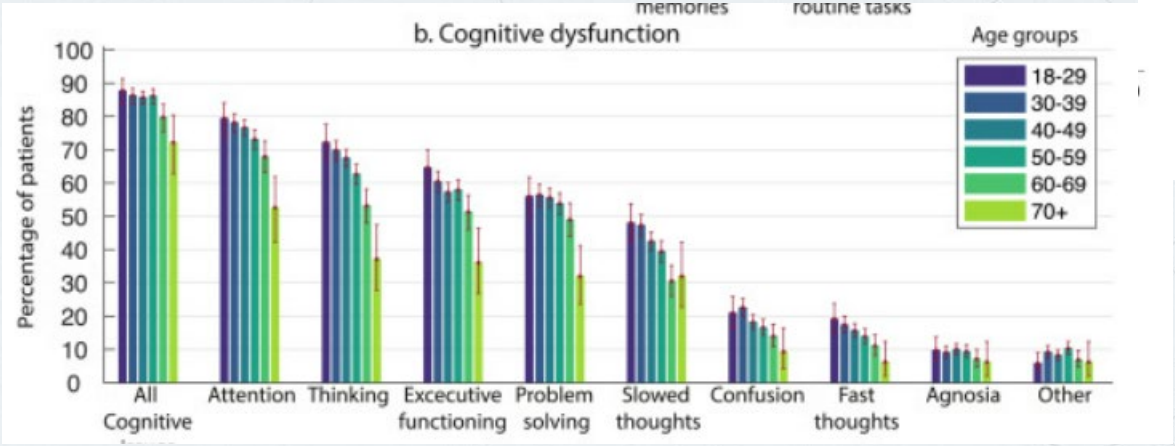

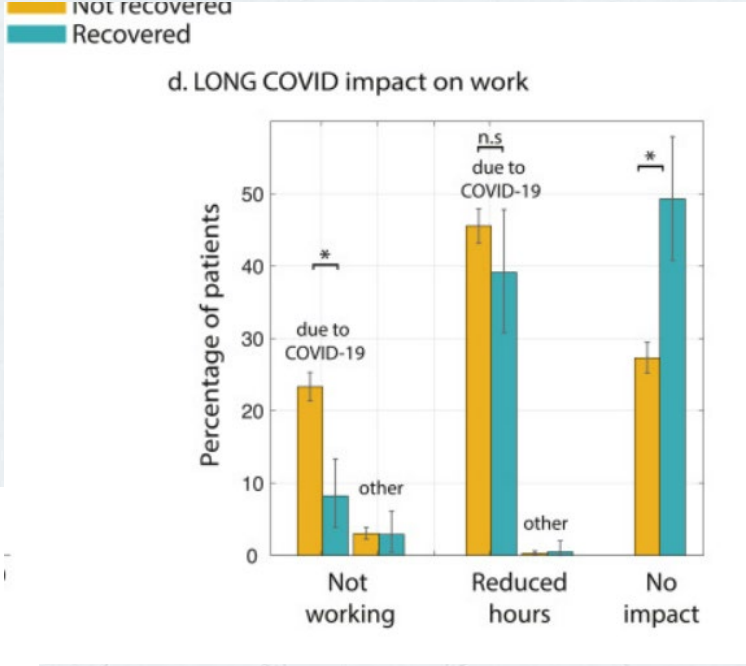

Davis, H. E. et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *eClinicalMedicine* 38, 101019 (2021). https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext

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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

Davis, H.E., McCorkell, L., Vogel, J.M. *et al.* Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146 (2023). https://doi.org/10.1038/s41579-022-00846-2

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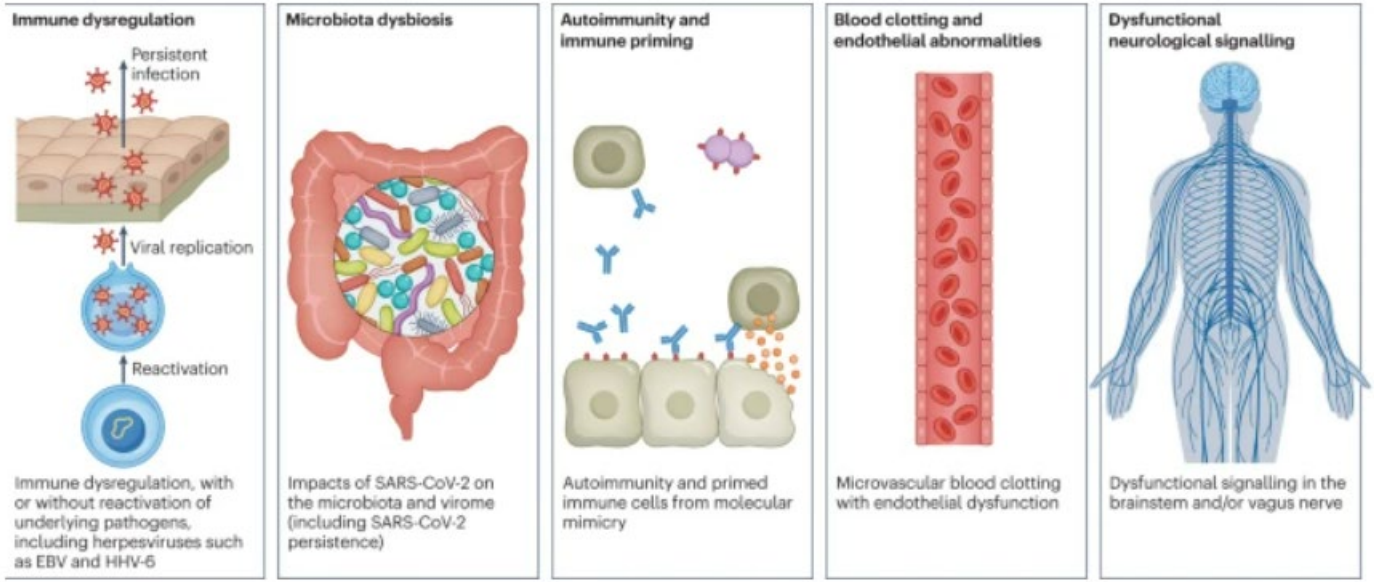
Fig. 3: Hypothesized mechanisms of long COVID pathogenesis.



Davis, H.E., McCorkell, L., Vogel, J.M. *et al.* Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146 (2023). https://doi.org/10.1038/s41579-022-00846-2

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Article | Published: 10 May 2023

Factors associated with psychiatric outcomes and coping in Long COVID

Yochai Re'em, Elisabeth A. Stelson, Hannah E. Davis, Lisa McCorkell, Hannah Wei, Gina Assaf & Athena Akrami

Nature Mental Health **1**, 361–372 (2023) | Cite this article

Re'em, Y., Stelson, E.A., Davis, H.E. *et al.* Factors associated with psychiatric outcomes and coping in Long COVID. *Nat. Mental Health* 1, 361–372 (2023). https://doi.org/10.1038/s44220-023-00064-6

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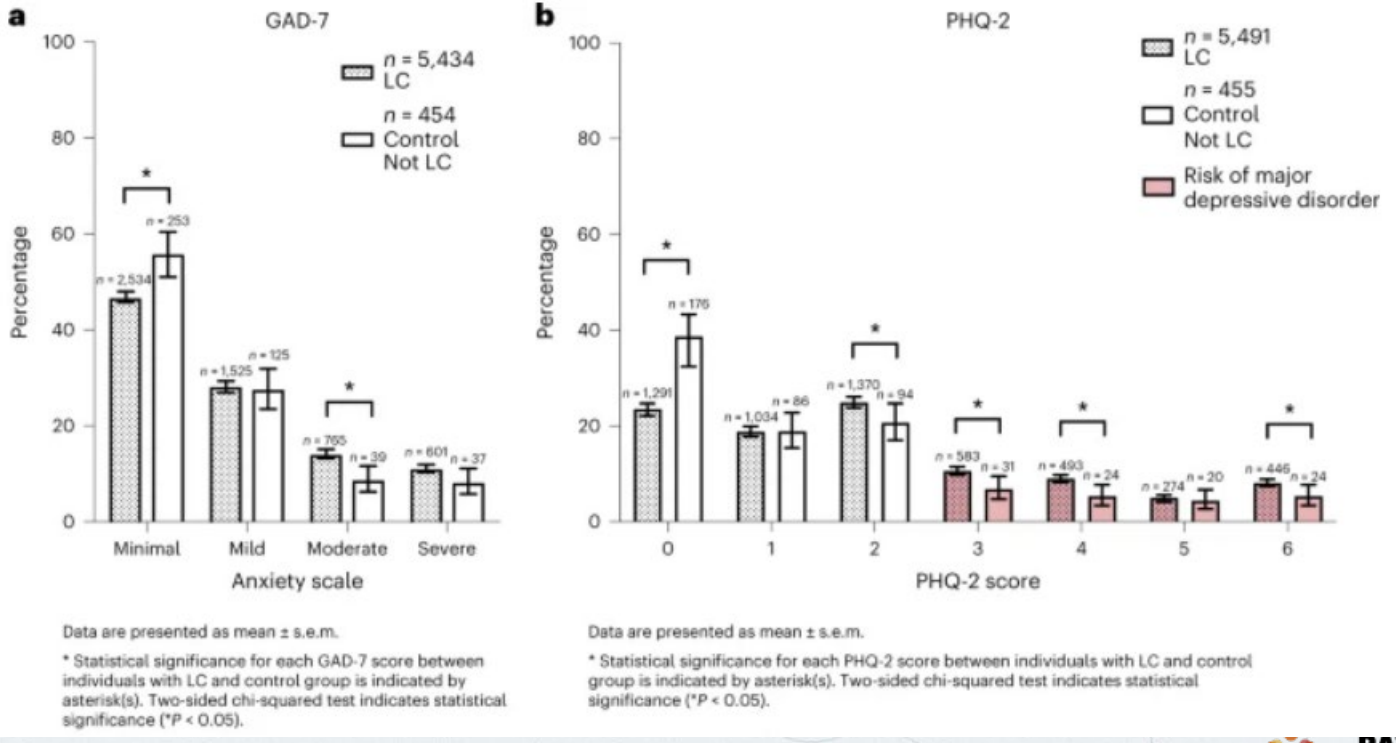
Fig. 1: Mental health symptoms of long COVID (LC) patients compared to patients without long COVID.



Data are presented as mean ± s.e.m.

* Statistical significance for each GAD-7 score between individuals with LC and control group is indicated by asterisk(s). Two-sided chi-squared test indicates statistical significance (*P < 0.05).

Data are presented as mean ± s.e.m.

* Statistical significance for each PHQ-2 score between individuals with LC and control group is indicated by asterisk(s). Two-sided chi-squared test indicates statistical significance (*P < 0.05).

Re'em, Y., Stelson, E.A., Davis, H.E. *et al.* Factors associated with psychiatric outcomes and coping in Long COVID. *Nat. Mental Health* 1, 361–372 (2023). https://doi.org/10.1038/s44220-023-00064-6

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MINI REVIEW article

Front. Rehabil. Sci., 28 April 2023
Sec. Interventions for Rehabilitation
Volume 4 - 2023 | https://doi.org/10.3389/fresc.2023.1122673

This article is part of the Research Topic
Post-Acute COVID Rehabilitation
View all 4 Articles >

Female reproductive health impacts of Long COVID and associated illnesses including ME/CFS, POTS, and connective tissue disorders: a literature review

Beth Pollack[1],  Emelia von Saltza[2],  Lisa McCorkell[2*], Lucia Santos[2], Ashley Hultman[2], Alison K. Cohen[2,3] and Letícia Soares[2*]

Pollack B, von Saltza E, McCorkell L, Santos L, Hultman A, Cohen AK, Soares L. Female reproductive health impacts of Long COVID and associated illnesses including ME/CFS, POTS, and connective tissue disorders: A literature review. Frontiers in Rehabilitation Sciences 4 (2023). https://doi.org/10.3389/fresc.2023.1122673

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Female Reproductive Conditions in Long COVID, ME/CFS, POTS, and EDS*

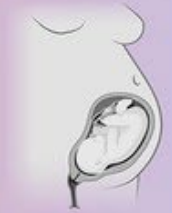
Menstrual

- Menstrual cycle irregularities [LC, ME/CFS]
- Excessive menstrual bleeding [LC, ME/CFS, EDS]
- Symptom exacerbation around periods [LC, ME/CFS, POTS]
- Amenorrhea and Oligomenorrhea [LC, ME/CFS, POTS]
- Premenstrual syndrome symptoms [LC]
- Dysmenorrhea [EDS]
- Bleeding between periods [ME/CFS, EDS]

Gynepathologies

- Premature ovarian insufficiency [LC]
- Endometriosis [LC, ME/CFS, POTS]
- Ovarian dysfunction [LC]
- Dyspareunia [EDS]
- Vulvodynia [EDS]
- Ovarian cysts and polycystic ovarian syndrome [ME/CFS, POTS]
- Uterine fibroids and bleeding [POTS]
- Pelvic congestion syndrome [POTS]
- Non-menstrual pelvic pain [ME/CFS]

Fertility and Pregnancy



- Fertility issues [LC, EDS]
- Higher risk of maternal mortality from childbirth [EDS]
- Higher risk of premature birth, miscarriage, stillbirths, placenta previa, preterm premature rupture of membranes, cervical incompetence, antepartum hemorrhage, intra-uterine growth restriction, delivery by C-section, spontaneous abortions, and longer postpartum hospital stays [EDS]
- Pregnancy can trigger and/or alter the course of illness [ME/CFS, POTS]

Menopause

- Premature menopause [LC, ME/CFS]
- Postmenopausal bleeding [LC]
- Symptom exacerbation in perimenopause and postmenopause [ME/CFS]

Pollack B, von Saltza E, McCorkell L, Santos L, Hultman A, Cohen AK, Soares L. Female reproductive health impacts of Long COVID and associated illnesses including ME/CFS, POTS, and connective tissue disorders: A literature review. Frontiers in Rehabilitation Sciences 4 (2023). https://doi.org/10.3389/fresc.2023.1122673

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HIGHLIGHTS OF OTHER WORK

RESEARCH

- Impacts of **Reinfections** on people with LC
- Mixed methods study of Long COVID's impact on **Employment and quality of life**

PUBLICATIONS

- **Patient-Generated Hypotheses** journal for Long COVID and associated conditions
- Collaboration with Council of Medical Specialty Societies **creating scorecards for meaningful patient engagement**, involving patient-experts at every stage of the research process

$5MIL BIOMEDICAL RESEARCH FUND

- **$5M Biomedical research fund** for Long COVID. Awarded by a panel of patient-researchers

ADVOCACY

- **Use data and patient experience to advocate for better research, clinical guidelines, and policy** in recommendations to Congress, HHS, NIH, CDC, WHO, & more

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RESEARCH WITH PATIENT PERSPECTIVE

RELEVANT

Researchers, in partnership with patients, set research agendas based on **emerging priorities that directly serve patients**

DIFFERENT INCENTIVE STRUCTURES

Patients are driven out of an incentive of desperation and **improving their quality of life**. Not trying to make a career, so **can take more risks**

EFFECTIVE

Research questions **respond to patient community insights and ensure research is reflective of lived experiences,** leading to faster and more accurate results

IMPACT-DRIVEN

Research is **widely disseminated** in open-access academic journals, social media and within patient advocacy communities and **created to have an impact**

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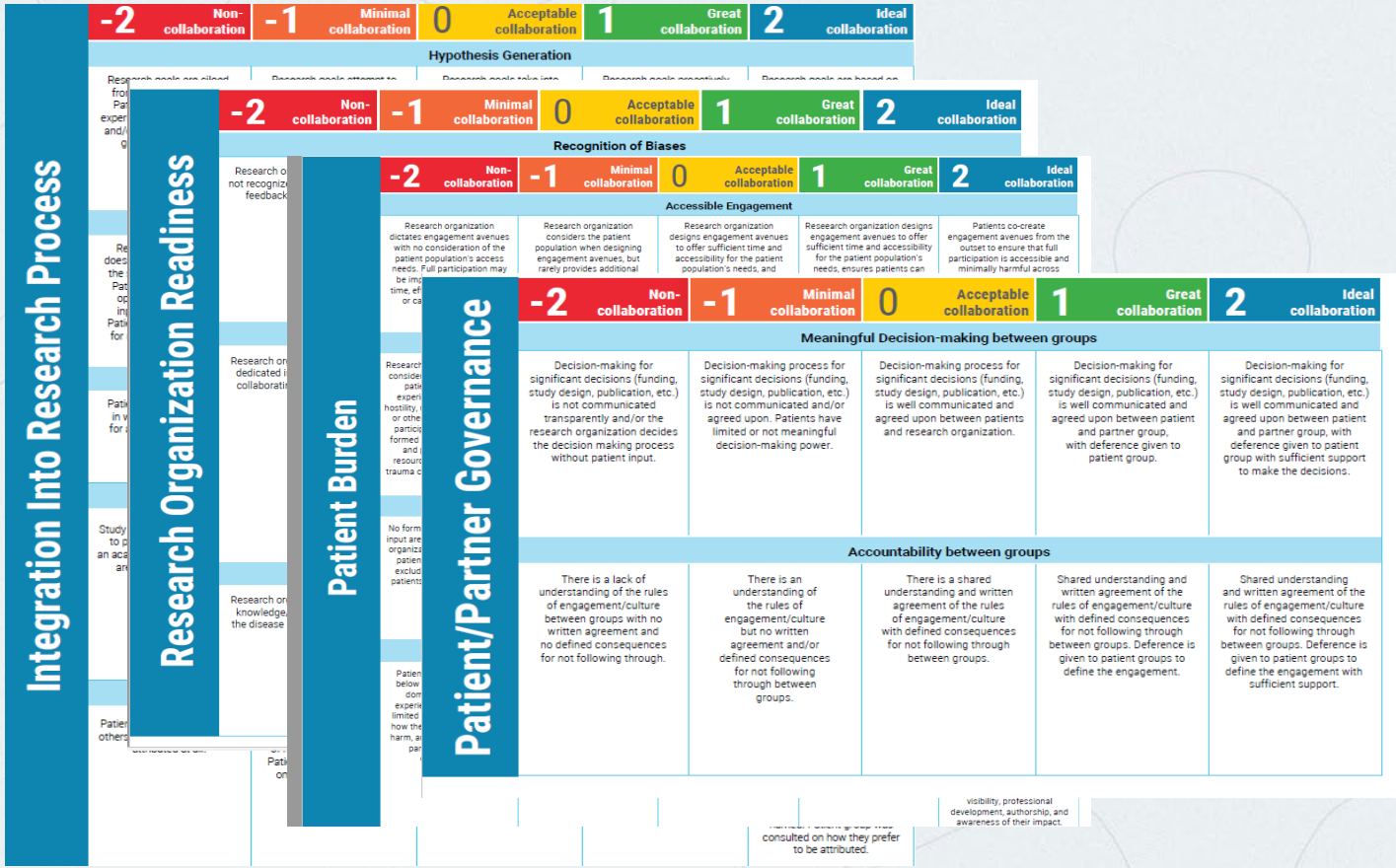

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Integration Into Research Process

-2 Non-collaboration	-1 Minimal collaboration	0 Acceptable collaboration	1 Great collaboration	2 Ideal collaboration
Hypothesis Generation				
Research goals are siloed from patients' priorities. Patient org's questions and experiences are not included and/or dismissed when generating research hypotheses.	Research goals attempt to involve patients' priorities, but is limited by communication or collaboration. Patients org's inquiries and lived experiences are rarely includedwhen generating research hypotheses. Patients may have suggested the research question with no further involvement.	Research goals take into account patients' priorities. Patient org's inquiries and lived experiences are included when generating research hypotheses.	Research goals proactively address patients' priorities with sufficient ongoing collaboration. Patients org's inquiries and lived experiences are included when generating research hypotheses.	Research goals are based on patients' priorities and co-written by patient organization or patient-researchers. Patients organization's inquiries and lived experiences share an equal weight with research organization's interests when generating research hypotheses.
Study Design				
No involvement of patients in the study design process. Patients do not have the opportunity to review and comment. Patient groups may be contacted only for study recruiting.	No involvement of patients in the study design process. Patients may be invited to review study design but feedback is mostly ignored by research organization and no functioning accountability system is in place. Patient groups may be contacted for study recruiting purposes only.	Select patient voices are approached to inform the study design. Patient orgs are invited to review study design and have an impact on the study design.	Patient organization and their community's input is proactively invited to help inform the study design. Patient organizations are invited to review study design and patient feedback changes the study design.	Study design is co-written and reviewed by patient-researchers. If applicable, protocol testing is done by the patient community.
Analysis				
Patients have no say in what data to prioritize for analysis and methods of analysis.	Patients are asked to review drafts but have little say in what data to prioritize for analysis and methods of analysis.	Patients or patient organization is involved in interpreting data and carrying out analysis in some capacity.	Patients or patient organization is involved in interpreting data and carrying out analysis anywhere in the study.	Patient-researchers lead on the interpretation and analysis and/or work concurrently with partner org's research team to carry out analysis
Publication				
Study results are inaccessible to patients and/or behind an academic paywall. Findings are not communicated in lay terms.	Study results are inaccessible to patients and/or behind an academic paywall. Findings are summarized in lay terms.	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.	Study results are freely accessible to patients and the public. Findings are summarized in lay terms and are actively disseminated to patient population. A channel of communication is available for patients to ask questions of the research partner.
Attribution				
Patients' work is attributed to others and/or patients are not attributed at all.	Patients are listed as being involved without a description of how they were involved. Patient group was not consulted on how they prefer to be attributed.	Patient group is acknowledged/credited in major public facing communication (press, announcements, papers), to the extent that patient group wishes to be named. Patient group was consulted on how they prefer to be attributed.	Patient group is credited in all public facing communication and included as authors on papers, to the extent that patient group wishes to be named. Patient group was consulted on how they prefer to be attributed.	Patients are acknowledged specifically for what they did throughout the engagement process, are credited in all public facing communication, and included as authors on papers, to the extent that patient group wishes to be named. Patient group was consulted on how they prefer to be attributed.

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What Would a Patient-Driven Research Agenda Look Like?

- Ensuring meaningful engagement of patients/caregivers in all stages of the research process
- Incentivizing meaningful engagement of patients/caregivers
- Integrating new and existing evidence across infection-associated chronic conditions
- Accelerating clinical trials of therapeutics that are of priority to the patient community (e.g. antihistamines, anticoagulants, JAK-STAT inhibitors, and immunomodulators), with quality of life and functional ability endpoints
- Establishing an Office for Infection-Associated Chronic Illnesses in the NIH Director's Office

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Thank you!

Contact our team:

- Email: team@patientledresearch.com
- Social media: @patientled

Contact me:

- Email: lisa@patientledresearch.com
- Twitter: @LisaAMcCorkell

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References

- **Nature Review:** Davis, H.E., McCorkell, L., Vogel, J.M. *et al.* Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* 21, 133–146 (2023). https://doi.org/10.1038/s41579-022-00846-2
- **200 symptoms paper:** Davis, H. E. et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *eClinicalMedicine* 38, 101019 (2021). https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext
- **First Paper on Long COVID:** Assaf, G. et al. What Does COVID-19 Recover Actually Look Like? An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team. https://patientresearchcovid19.com/research/report-1/
- **Scorecards:** https://cmss.org/wp-content/uploads/2023/01/11231_CMSS_Plybk_Scorecards_FINAL.pdf
- **Patient-Generated Hypotheses Journal:** https://patientresearchcovid19.com/patient-generated-hypotheses-issue-may-2023/
- **Mental Health Paper:** Re'em, Y., Stelson, E.A., Davis, H.E. *et al.* Factors associated with psychiatric outcomes and coping in Long COVID. *Nat. Mental Health* 1, 361–372 (2023). https://doi.org/10.1038/s44220-023-00064-6
- **Reproductive Health Paper:** Pollack B, von Saltza E, McCorkell L, Santos L, Hultman A, Cohen AK, Soares L. Female reproductive health impacts of Long COVID and associated illnesses including ME/CFS, POTS, and connective tissue disorders: A literature review. Frontiers in Rehabilitation Sciences 4 (2023). https://doi.org/10.3389/fresc.2023.1122673
- **History of PLRC and patient-led research:** McCorkell, Lisa; S. Assaf, Gina; E. Davis, Hannah; Wei, Hannah; Akrami, Athena. Patient-Led Research Collaborative: embedding patients in the Long COVID narrative. PAIN Reports 6(1):p e913, DOI: 10.1097/PR9.0000000000000913

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