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# Catalyst Films about Health Experiences: Long COVID in Primary Care



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HealthExperiencesUSA  
*Bringing patients' voices to American healthcare*



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## Use of the Toolkit



The Catalyst Films about Health Experiences: Long COVID in Primary Care toolkit, available at <http://www.hipxchange.org/toolkit/LongCOVIDCatalystFilms>, is licensed under a [Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License](#).

The Catalyst Films about Health Experiences: Long COVID in Primary Care toolkit exists for the benefit of the health care community. These materials are available free of charge and can be used without permission; however, we ask that you register with HIPxChange prior to using the toolkit so that we may provide information on usage to our funders. It is acceptable to link to this website without express permission. If you decide to use these materials, we ask that you please credit the University of Wisconsin – Madison Department of Medicine, the UW-Madison Center for Patient Partnerships and the UW Health Innovation Program.

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## Background

The devastating impact of the COVID-19 pandemic in the U.S. continues to grow as additional variants yield new waves of infection. An estimated 1 in 5 people who have had COVID-19 will experience “long COVID” – persistent symptoms of acute SARS-CoV-2 infection lasting beyond three weeks (post-acute) or three months (chronic) after acute infection (National Center for Household Statistics, 2023). Among those dealing with long COVID, 79% have limitations to their day-to-day activities and 27% describe significant limitations (Burns, 2023). Primary care clinicians report feeling helpless and ineffective in their care of people with long COVID (Ollive, 2021).

**“We don’t know what to do to help patients with long COVID...[or have] a realistic idea of what is coming in the future.” – Dr. Sarina Schrager, clinician collaborator**

Primary care’s focus on long-term care relationships and community input position it well to bridge documented gaps between patients with long COVID and healthcare systems (Phillips et al., 2021) and to build trust by confronting structural inequities exposed and exacerbated by the COVID-19 pandemic (Berger et al., 2021; IQVIA, 2021).

This action-oriented toolkit includes a catalyst film which summarizes findings from research about patients’ and community members’ experiences with long COVID and resources for patients with long COVID and their clinicians. Together these materials, along with a facilitation guide and evaluation plan, compose an educational intervention for primary care that is intended to spark conversation and catalyze change in health care.

### Who should use this toolkit?

This toolkit is intended as an educational intervention for primary care clinicians and staff working with people with long COVID. The intervention is designed to increase the capacity and confidence of people caring for patients with long COVID in primary care clinics.

### What does the toolkit contain?

This toolkit contains materials for the educational intervention:

1. **Catalyst film:** Catalyst films about Health Experiences are short films that summarize key findings from interviews with people discussing their health experiences and

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experiences receiving health care. This catalyst film is about peoples' experiences of long COVID that includes practical guidance for primary care clinicians.

2. **Facilitation guide:** The toolkit contains facilitation materials including a draft agenda for the intervention session(s) using the catalyst film and tip sheets.
3. **Companion materials:** The toolkit also includes one-page sheets for patients with long COVID and clinicians with resources and tips for addressing this chronic health crisis. We offer samples and blank templates to customize for your location.
4. **Evaluation:** This toolkit includes a pre-post evaluation plan which will help you survey primary care clinicians exposed to the intervention to better understand its impact.

## How should these tools be used?

The materials in this toolkit can be used to:

1. Inform primary care clinicians about peoples' experiences of long COVID
2. Spark conversations about amplifying or changing certain clinical practices
3. Offer clinicians resources for assisting patients with long COVID

A copy of the survey instruments and information on adapting them are available in the PDF file. In addition, we provide a separate Microsoft Word/Excel file that you can download on the HIPxChange website to allow you to adapt the instruments for use in your organization.

## Development of this toolkit

The Catalyst Films about Health Experiences: Long COVID in Primary Care toolkit was developed by researchers and clinicians (Principal Investigator: Rachel Grob) at the University of Wisconsin-Madison School of Medicine & Public Health – Department of Family Medicine and Community Health. We also want to acknowledge the work by Claire Maske to make this toolkit possible.

In 25 interviews with people suffering with long COVID we conducted in Wisconsin from 2020-2022, we heard about the multifactorial physical, mental, economic, and social impacts of this emerging condition. We also learned about interviewees' actionable ideas for addressing long COVID in primary care clinics and in their communities. In 2023, we also interviewed 15 mental health providers, community health workers, lawyers, physicians and nurses, program managers, and home visitors to learn about existing resources and creative ideas for how to care for people with long COVID.

This project was supported by a Clinical and Community Outcomes Grant from the Institute for Clinical and Translational Research. Additional support was provided by the University of Wisconsin School of Medicine and Public Health's Health Innovation Program (HIP) and the Community-Academic Partnerships core of the University of Wisconsin Institute for Clinical and Translational Research (UW ICTR), grant 9 U54 TR000021 from the National Center for Advancing Translational Sciences (previously grant 1 UL1 RR025011 from the National Center for Research Resources). Source material for the film was generated with thanks to a Department of Family Medicine and Community Health Small Grant. The content is solely the

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responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or other funders.

Please send questions, comments and suggestions to [gherlab@fammed.wisc.edu](mailto:gherlab@fammed.wisc.edu).

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## Catalyst Film

The long COVID catalyst film was created through a stakeholder engaged process with patient partners who participated in patient experience interviews and clinical and research colleagues at the Wisconsin Research and Educational Network (Davis et al. 2022). This film was created from footage from virtual interviews with 25 people living with long COVID and information from 15 interviews with community resources providers responding to legal, medical, and social issues related to the long-term impacts of COVID-19. Designed through a multi-stakeholder engaged process, catalyst films contain clips that were selected because they represent common patterns. Animations are based on learnings from interviews with community resources providers.

Ideally, this and other catalyst films should be viewed as a group with time for reflection and discussion. The methodology used to develop this catalyst film is further described in the Catalyst Films about Health Experiences Guidebook Toolkit available at <https://www.healthexperiencesusa.org/CatalystFilms>.

## Companion Materials

These resource pages complement the film, adding specificity to tips and resources shared in the film animations. This toolkit contains a one-pager that clinicians and staff can give to patients with long COVID or that can be posted in clinical waiting and exam rooms. In addition, it includes a tip sheet for clinicians caring for patients with long COVID which includes tips for supporting employment, disability, and social support needs of patients.

These resource pages are intended as examples that can be adapted for local settings. A [template](#) to create a Patient Resources handout for your local area is available from Canva.com. Canva is free and relatively easy to use. In addition to adding local resources, we encourage you to verify the national resource list we have included; please note that the availability of these resources may change.

A [template](#) to create a Provider One-Sheet handout customized for your clinic is available from Canva.com. Canva is free and relatively easy to use. Since diagnostic criteria may change, review this section and update as needed.

## Facilitator Guide

We include facilitator guides for the intervention delivered in one session and across two sessions. The one-session guide includes time for completion of the pre-survey, if applicable, at the start of the session. In general, our experiences in the pilot suggest that the intervention is best delivered in one session but acknowledge that schedules may require delivery across two sessions.

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When this intervention was first piloted, it took place virtually. Although facilitator guides offer instructions for virtual engagement including the use of recording and chat functions, the overall content of these guides can be easily adapted for in-person sessions.

We recommend at least three research team members be present for the intervention – one facilitator, one back-up facilitator, and (if virtual) one team member to manage the recording if applicable, chat, and troubleshoot any technical issues.

## Evaluation Survey

The pre- post-evaluation surveys are intended to be answered by primary care clinicians to gather information about individual-level outcomes and perceptions of learning cultures at their workplaces. The post-survey aims to measure impacts of the intervention on their approach to their patients with long COVID in their practice.

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