

Infection-Associated Chronic Conditions: Opportunities for Action

Summer 2023 Workshop Series Summary & Key Takeaways

Prepared for the CDC Foundation by:



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Project Overview

Infection Associated Chronic Conditions (IACCs) are chronic medical conditions that are initially triggered by an infection. While many different pathogens have been associated with the development of IACCs, different IACCs share several common features:

- IACCs tend to cause severe impacts to quality of life;
- IACCs typically impact a disproportionately high rate of female patients;
- IACCs are often characterized by neurological or immunological pathology; and
- IACCs comprise diffuse organ system interactions; and require multidisciplinary care.¹

Millions of Americans were living with IACCs prior to the COVID-19 pandemic, but the exact number is unknown. Large-scale epidemiological studies identifying the number or percentage of Americans with any IACC has not been undertaken to date. US population estimates of just a few IACCs published before or at the start of the COVID-19 pandemic suggest that these conditions were already widespread (Table 1).

Table 1: Number of People in the United States Estimated to Have Select IACCs

Estimated # of People in the U.S. with Condition	Year of Publication	Selected IACC
400,000 to 3,100,000	2008	Sjogren’s disease ²
851,749 to 913,925	2017	multiple sclerosis ³
1,000,000 to 3,000,000	2019	postural orthostatic tachycardia syndrome (POTS) ⁴
1,619,988 to 2,304,147	2020	persistent/chronic Lyme disease ^{5,6}

¹ Choutka et al. Nature Medicine | VOL 912 28 | May 2022 | 911–923

² Helmick CG, Felson DT, Lawrence RC, Gabriel S, et al. Estimates of the prevalence of arthritis and other rheumatic conditions in the United States: Part I. Arthritis & Rheumatism. 2008 Jan, 58: 15-25.

³ Wallin MT, Culpepper WJ, Campbell JD, Nelson LM, et al. The prevalence of MS in the United States A population-based estimate using health claims data. Neurology. Mar 2019, 92 (10) e1029-e1040.

⁴ Harris CI. COVID-19 Increases the Prevalence of Postural Orthostatic Tachycardia Syndrome: What Nutrition and Dietetics Practitioners Need to Know. J Acad Nutr Diet. 2022 Sep;122(9):1600-1605. doi: 10.1016/j.jand.2022.06.002. Epub 2022 Jun 10. PMID: 35697326; PMCID: PMC9186518.

⁵ DeLong A, Hsu M, Kotsoris H. Estimation of cumulative number of post-treatment Lyme disease cases in the US, 2016 and 2020. BMC Public Health 19, 352 (2019).

⁶ While the article cited references “post-lyme”, we have elected to use the terms preferred by patient advocacy organizations.

3,300,000	2021-2022	myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) ⁷
12,730,000 to 20,000,000	2023	long COVID ⁸

Because of their systemic nature and diffuse symptoms, IACCs also tend to share common gaps and challenges between them, including that many lack effective treatments and that most medical curricula and educational materials lack mention of IACCs. Many IACC patients report feeling dismissed by healthcare providers who may not understand IACCs or may not have ready treatments for them.⁹

Due to these challenges and the number of Americans living with IACCs, these conditions would benefit from increased focus from the healthcare and research communities to address critical gaps.

It is within this context that the CDC Foundation, with support from the Centers for Disease Control and Prevention (CDC), launched the Infection Initiated Chronic Conditions Understanding and Engagement (ICUE)¹⁰ program in December 2022. The project brought together IACC patient advocacy groups and community-based organizations (CBOs) focused on raising awareness and helping people living with IACCs to identify common priorities and opportunities to collaborate, including exploring the development of an IACC Patient Advocacy Coalition (IACCPAC).

Opportunities for Action

The ICUE project team comprised representatives from the CDC Foundation, Commonality, Inc. and the Long COVID Alliance (LCA). Contributing LCA leaders included Solve ME/CFS,

⁷ Vahratian A, Lin JS, Bertolli J, Unger ER. Myalgic encephalomyelitis/chronic fatigue syndrome in adults: United States, 2021–2022. NCHS Data Brief, no 488. Hyattsville, MD: National Center for Health Statistics. 2023. DOI: <https://dx.doi.org/10.15620/cdc:134504>

⁸ National Center for Health Statistics. U.S. Census Bureau, Household Pulse Survey, 2022–2023. Long COVID. Generated interactively: from <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>; Ford ND, Slaughter D, Edwards D, et al. *Long COVID and Significant Activity Limitation Among Adults, by Age – United States*, June 1–13, 2022, to June 7–19, 2023. MMWR Morb Mortal Wkly Rep 2023;72:866–870. DOI: <http://dx.doi.org/10.15585/mmwr.mm7232a3>

⁹ Long COVID Alliance and CDC Foundation. *Infection Associated Chronic Conditions Workshop 1*. Unpublished Workshop Findings from the Infection Initiated Chronic Conditions Understanding and Engagement (ICUE) Project. July 11, 2023.

¹⁰ CDC Foundation. (2022, December 5). *New CDC Foundation Program Focused on Creating Partnerships to Address Chronic Conditions Caused by Infections, Including Long COVID* [Press Release]. Available Online: <https://www.cdcfoundation.org/new-partnership-ICUE-Long-COVID>

Dysautonomia International, COVID-19 Longhailer Advocacy Project and Patient-Led Research Collaborative. Collectively, these organizations developed two virtual engagement sessions on July 11, 2023, and August 7, 2023, with more than 60 participants across 27 IACC patient advocacy organizations toward the achievement of the following goals:

- Bring together diverse disease groups and patient organizations to promote collaboration to address shared challenges.
- Strengthen cross-sector partnerships among disease groups to identify common objectives and actionable steps for the community.
- Build community among IACC groups representing less well-understood and/or resourced IACCs while also determining opportunities for collective action.

The workshop findings substantiated a need for coordinated, collective action among IACC organizations and led to the development of the IACC Patient Advocacy Coalition (IACCPAC). Through workshop activities, three main outputs were identified as priorities for the IACCPAC:

- 1) **Purpose framework:** five essential tenets that should be the basis to inform the coalition's strategic direction.
- 2) **Priorities for collective action:** five main objectives the coalition should collectively advance to support patient needs.
- 3) **Activities:** actions the coalition should take to achieve each priority.

Note that while these items and actions were identified through the ICUE gap analysis, some of these may be prioritized in future projects outside of ICUE with non-federal funding.

Purpose Framework

- Build capacity to support the work of patients and partner organizations.
- Honor the legitimacy of lived experience.
- Ensure an equity perspective in IACC work by honoring the voice of historically marginalized, neglected, under resourced, and/or under researched communities, including, but not limited to, Black, Indigenous, Hispanic, Asian and other people of color, as well as Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual communities, people with disabilities, individuals with lower incomes, and individuals living in rural settings.
- Open pathways to reduce the complexity of care.
- Establish and strengthen relationships between partners to grow IACC champions and allies.

Priorities for Collective Action

- Promote comprehensive research
- Enhance patient and caregiver quality of life
- Advance public awareness of IACCs
- Modernize health systems
- Support clinician education

Potential Activities to Support Collective Priorities

Promote Comprehensive Research

- Create a collective IACC research agenda.
- Develop a central hub/database for trials, treatments and patient registry.
- Inform the establishment of patient-centered research actions to help ensure research designs support diverse communities and are of high quality.
- Collaborate with the private sector to provide seed funding for non-federal projects.
- Train, invest and empower patient leaders to be active partners at every stage of the research process.
- Support partners to identify the epidemiology, disease burden, and socio-economic impacts of IACCs.

Enhance Patient and Caregiver Quality-of-Life

- Educate on the gaps and needs related to developing best practices to support patients in schools, workplaces, and community spaces, such as increasing awareness on IACCs as a disability, as well as accommodations and services available, etc.
- Develop caregiver and family education and resources.
- Develop patient education and resources.
- Explore the feasibility of establishing financial aid and other assistance to support patients and caregivers with the demands of living with an IACC.

Advance Public Awareness of IACCs

- Create a public awareness campaign in collaboration with providers, medical associations, etc. to educate patients and caregivers about IACCs.
- Educate the media to ensure IACCs are represented in a fair and factual way that legitimizes patient lived experience.
- Recruit trusted champions/spokespeople to publicly discuss and educate on the experience of living with an IACC, the prevalence of IACCs, etc.

- Create public-facing campaigns to counter stereotypes, stigma, and/or misconceptions about how IACCs develop, to highlight the experience of living with an IACC, and educate on the long-term health implications of IACCs.
- Attend and present at conferences and events to increase awareness and education on IACCs.

Modernize Health Systems

- Partner with medical associations and other health system key partners to inform the development of medical guidelines/care algorithms for IACCs.
- Research/identify ways to leverage technology to improve patient care.
- Partner with private healthcare insurance companies to educate on the need to expand coverage of IACC-related care and treatment benefits.
- Educate on the need for an IACC care coordination system that supports integrated patient care across different domains, conditions, and disciplines.

Support Clinician Education

- Develop educational resources and platforms to inform health care providers on the administrative aspects of navigating IACC care.
- Collaborate with medical associations and universities to innovate clinician education and training on IACCs for both new and existing healthcare practitioners.
- Educate on the need for the development of a new medical specialty focusing on IACCs.
- Create campaigns to reduce healthcare practitioner bias and increase culturally competent care towards patients with IACCs.
- Promote pipelines and opportunities for new and early career medical providers to specialize in the IACC field.

Roadmap for the Future

There are many actions anyone can take, even today, to support the needs of the IACC community.

- Sign up for the IACC coalition email list to hear important updates on how to get involved as the coalition moves forward. Sign up at: contact@iaccpac.org.
- If you're interested in volunteering to support the IACC coalition's development, let us know by emailing contact@iaccpac.org.
- Share this report on social media.

- Let your contacts know what IACCs are, and the huge impact they have on individuals, families, and society.
- Start using the #IACC hashtag when discussing any of the IACCs on social media.
- Learn about IACCs that are different from your IACC(s) of interest. When we are all educated about the experiences and needs of each IACC community, we will be better able to support each other and find shared opportunities.
- If you speak or write about one or more of the IACCs, amplify the IACC concept and discuss the other IACCs in the context of your IACC(s) of interest. A rising tide lifts all boats!

Appendix A: Collaborators

Workshop Participants

- Ability 1st Utah
- Bay Area Lyme Foundation
- BIPOC Equity Agency
- Caregiver Wisdom
- CDC Foundation
- Center for Lyme Action
- Commonality
- COVID-19 Longhailer Advocacy Project
- Dysautonomia International
- HHV-6 Foundation
- The Louisa Adelynn Johnson Fund for Complex Disease
- Lyme Disease Biobank
- LymeDisease.org
- Massachusetts ME/CFS & FM Association
- #MEAction
- Minnesota ME/CFS Alliance
- Multiple Sclerosis Association
- The National Alliance for PANS/PANDAS Action (NAPPA)
- Neuroimmune Foundation
- NMUNDA
- Open Medicine Foundation
- Partnership for Tick-Borne Diseases Education
- Patient-Led Research Collaborative
- Simmaron Research
- Sjogren's Advocate
- Sjogren's Foundation
- Solve M.E.
- Steven & Alexandra Cohen Foundation
- Super T's Mast Cell Foundation

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