



Advancing Clinical Registries to Support Pandemic Treatment and Response

About the Series: The Council of Medical Specialty Societies (CMSS) webinar series will address key questions related to the rapid development, deployment and implementation of Covid-19 focused clinical registries and clinical repositories by specialty societies and academia.

Upcoming Free Webinar: Aug. 12 | 1:00 - 2:30 pm ET
**Prioritizing Patient Engagement and Inclusion
of Patient-Generated Covid-19 Data**

ABOUT THE WEBINAR:

This webinar will provide perspectives on:

- How people living with health conditions are reliable sources of information and can contribute to the advancement of society through research, particularly in the investigation of complex and novel diseases.
- Preparing for the future of integrated registries, driven by key partners and data providers, including patients and caregivers.
- Building a biomedical research enterprise that incorporates self-collected time-series observations generated by patients.
- How networked patients can help amplify the work of clinical registries and guide frontline clinicians to the latest research.

PANELISTS:

Panelist Bios and Twitter Handles available on page 2

Moderator:

- **Susannah Fox**; Principal, Internet Geologist LLC; Former Chief Technology Officer, US Department of Health and Human Services

Host:

- **Helen Burstin, MD, MPH, MACP**; Chief Executive Officer, Council of Medical Specialty Societies (CMSS)

Panelists:

- **Gina Assaf**; Independent digital design consultant/Leading the Patient-Led Research Group within Body Politic
- **Hannah Davis**; Researcher with the Patient-Led Research Group within Body Politic
- **Emily Sirotych**; COVID-19 Global Rheumatology Alliance; Canadian Arthritis Patient Alliance; and Department of Health Research Methods, Evidence, and Impact, McMaster University
- **Gary Wolf**; Co-Founder, Quantified Self

Register for the Webinar:

CMSS Webinars are free to attend but registration is required. Register online:

<https://attendee.gotowebinar.com/register/9023040327154304012>

Join the Conversation:

Use **#COVIDRegistries** when tweeting about the webinar series

Follow **@CMSSMed** and visit [CMSS.org](https://www.cmss.org) for frequent updates



Moderator:

Susannah Fox

Principal, Internet Geologist LLC;
Former Chief Technology Officer, US
Department of Health and Human
Services [@SusannahFox](#)

Susannah Fox is the principal of Internet Geologist, LLC, a health and technology consultancy in Washington, DC. She is the former Chief Technology Officer for the U.S. Department of Health and Human Services, where she led an open data and innovation lab during the Obama Administration. She was previously the entrepreneur-in-residence at the Robert Wood Johnson Foundation, and for 14 years directed the health portfolio at the Pew Research Center's Internet Project where she helped create and define a new market at the intersection of health, social media, and patient engagement.



Host:

Helen Burstin, MD, MPH, MACP
Chief Executive Officer
Council of Medical Specialty Societies
(CMSS) [@HelenBurstin](#)

Helen Burstin, MD, MPH, MACP is the Chief Executive Officer of the Council of Medical Specialty Societies (CMSS) which represents 45-member specialty societies with collective membership of almost 800,000 U.S. physician members. CMSS works to support and strengthen specialty societies and catalyzes improvement through convening, collaboration, collective voice and action across specialties. CMSS also provides a proactive platform to assess and address emerging and critical issues across specialty societies that influence the future of healthcare and the patients we serve.



Gina Assaf

Independent digital design
consultant, Leading the Patient-Led
Research Group within Body Politic
[@GinaAssaf](#)

Gina Assaf is an independent digital strategist, researcher, and designer for the humanitarian and global aid sector. She has worked for both Silicon Valley tech companies and Global Aid and humanitarian organizations such as the United Nations, IRC, World Bank, USAID contractors, Intuit, and GitHub. She has conducted design research and technology design for multiple sectors including financial, education, agriculture, and global health. She is an expert in conducting human-centered design and research methods. She is currently leading the Patient-Led Research Volunteer Group within Body Politic.



Hannah Davis

Researcher with the Patient-Led
Research Group within
Body Politic
[@ahandvanish](#)

Hannah Davis is a research artist and generative musician working with data and machine learning. Pre-COVID, she was a speaker on topics like bias in machine learning, subjective data, and algorithmic music at places such as The Library of Congress, Bell Labs, and the Women in Data Science conference. She is a researcher with the Patient-Led Research Group within Body Politic.



Emily Sirotych

COVID-19 Global Rheumatology
Alliance; Canadian Arthritis Patient
Alliance; Department of Health
Research Methods, Evidence, and
Impact, McMaster University
[@emilysirotych](#)

Emily Sirotych is a PhD student in Health Research Methodology at McMaster University in Hamilton, Canada. Ms. Sirotych is passionate about data collection and patient/community engagement in all aspects of research. Her research interests include guideline development, rare diseases, and rheumatological disorders. Ms. Sirotych is also a Steering Committee member of the COVID-19 Global Rheumatology Alliance and Board Member of the Canadian Arthritis Patient Alliance.



Gary Wolf

Co-Founder, Quantified Self
[@quantifiedself](#) | [@agaricus](#)

Gary Wolf is the co-founder of The Quantified Self, a global collaboration among users and makers of self-tracking tools exploring "self-knowledge through numbers." His writing and academic research has appeared in The Best American Science Writing, Wired Magazine, The New York Times Magazine, Frontiers in Computer Science, Journal of Circadian Rhythms, BMJ Open, and other publications. In 2005-2006 he was a John S. Knight Fellow at Stanford University. In 2016 he was inaugurated as a visiting professor in the Professorship New Business & ICT of Hanze University of Applied Sciences, Groningen, where he and Dr. Martijn de Groot established the Quantified Self Institute.