



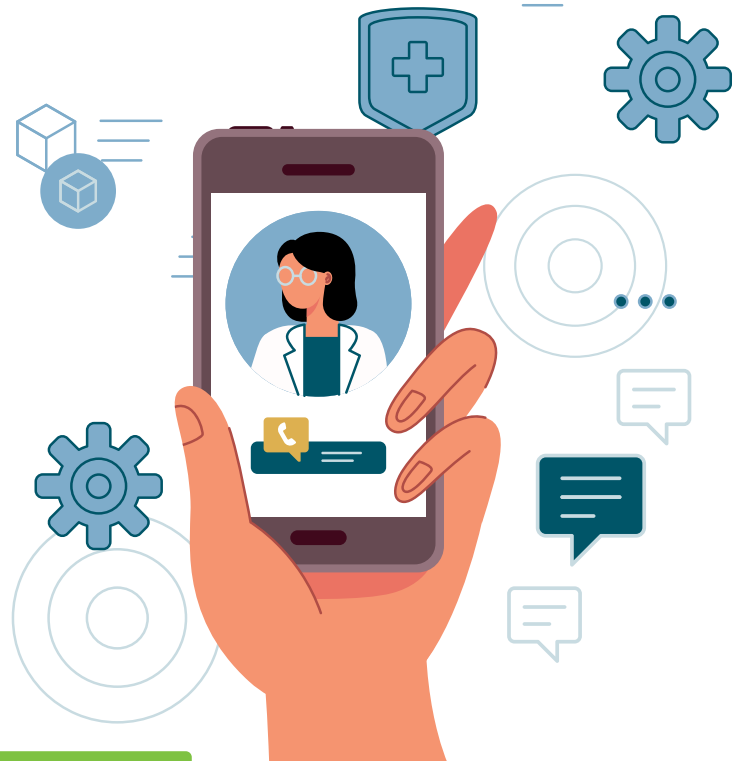
PROBLEM:

Local care models often applied to broad diseases can be unsuitable or even infeasible for rare disease patients who may have to travel long distances, sometimes with bulky specialized equipment such as respirators, to see specialists at rare disease Centers of Excellence¹. For patients with rare diseases, telehealth is a currently underutilized tool that could address the challenges of wide geographic dispersion, travel burden, and access to specialists⁴. Lessons from COVID-19 suggest that telehealth is a tool that can help more patients access high quality, appropriate care regardless of their geographic location, their ability to attend in-person appointments, or their condition.

While states mandate that Medicaid and private insurers provide coverage for telehealth to the same extent as coverage for in-person / local carepayer and access trends in telehealth vary widely with no two states defining, reimbursing, or regulating telehealth in the same way^{3,4,5,6}.

DEFINITIONS

Centers of Excellence: Specialized programs within healthcare institutions which supply exceptionally high concentrations of expertise and related resources centered on particular medical areas and delivered in a comprehensive, interdisciplinary fashion.



SOLUTION:

Standardized coverage across all states to non-conventional channels for healthcare delivery, like telehealth and specialty care pharmacies, to ensure equitable delivery of care and reduce care burden for rare disease patients. This includes adopting best practices observed and making flexibilities and expanded services applied to telehealth during the COVID-19 pandemic permanent.

Variability in care and access to care across state lines can also be addressed by managed care policies that seek to reduce variability and better align care approaches to the specific needs of rare disease patients.

SOURCES

1. Jones DEJ, Sturm E, Lohse AW. Access to care in rare liver diseases: New challenges and new opportunities. *J Hepatol.* 2018;68(3):577-585.
2. Alvandi M. Telemedicine and its Role in Revolutionizing Healthcare Delivery. *American Journal of Accountable Care.* 2017;5(1):e1-e5.
3. Donelan K, Barreto E, Sossong S, et al. Patient and clinician experiences with telehealth for patient follow-up care. *Am J Manag Care.* 2019;25(1):4044.
4. Center for Connected Health Policy. State Telehealth Laws and Reimbursement Policies. Fall 2019. <https://www.cchpca.org/sites/default/files/2019-10/50%20STATE%20INFOGRAPH%20FALL%202019%20FINAL.pdf>. Published 2019. Accessed June 2020.
5. Center for Connected Health Policy. State Telehealth Laws and Reimbursement Policies. Fall 2019. <https://www.cchpca.org/sites/default/files/2019-10/50%20STATE%20INFOGRAPH%20FALL%202019%20FINAL.pdf>. Published 2019. Accessed June 2020.
6. Dorsey E, Topol E. State of Telehealth. *N Engl J Med.* 2016;375(2):154-161.
7. Access to Critical Therapies White Paper <https://globalgenes.org/resources/guiding-principles-of-rare-disease-care-and-patient-access/>

ABOUT US

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf -- helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact Global Genes at 949-248-RARE or visit our resource hub at globalgenes.org.

CONTACT US • 28 Argonaut, Suite 150, Aliso Viejo, CA 92656 • +1-949-248-RARE (7273) • www.globalgenes.org

FOLLOW US @globalgenes.org

© Global Genes 2021. All Rights Reserved.