June 10, 2020

Dr. Steven D. Pearson
President
Institute for Clinical and Economic Review
Two Liberty Square, Ninth Floor
Boston, MA 02109

Dear Dr. Pearson:

As organizations representing older adults, people with disabilities and underlying conditions and their caregivers, we are writing to share concerns about ICER's *Alternative Pricing Models for Remdesivir and Other Potential Treatments for COVID-19.* The current COVID-19 crisis has upended the entire country and our communities are particularly vulnerable, being at heightened risk for severe disease when contracting the virus. In the face of this pandemic, disability rights organizations are fighting for the enforcement of civil rights laws to mitigate health care discrimination in the form of deprivation of healthcare services, like ventilators, in favor of other "healthier" individuals.

Therefore, our members stand to benefit most from innovative treatments for this aggressive virus. Yet, this new value assessment, also intended for use on future treatments for COVID-19, is riddled with methodological flaws due to its hasty development and completely ignores the tremendous amount of stakeholder feedback ICER has received over the last five years on its framework and processes. We are concerned that, if relied upon by policymakers, its implications would be particularly detrimental to caring for older adults and people with disabilities most at risk during this COVID-19 crisis.

No one supports affordability more than the older adults, patients and people with disabilities with a real stake in achieving access to treatments in this pandemic, yet we also know the implications for access that emerge from value assessments that arbitrarily diminish a treatment's value and lead payers to restrict their coverage. We have consistently raised the red flag that ICER's value assessments are methodologically flawed and not fit for the purpose of making decisions related to coverage, reimbursement and incentive programs by policymakers and payers. The latest assessment from ICER validates our concerns.

This cost effectiveness model devalues the lives of older adults. Cost effectiveness analyses using QALYs have long been critiqued for bias against older patients with fewer life years to be gained by treatment, a core rationale for Congress banning use of QALYs in Medicare in 2010. As recently as last year, the National Council on Disability, an independent government agency, issued a report calling for a more comprehensive ban on use of QALYs in our health system due to their implications for violating existing civil rights laws, including the ADA, Section 504, and Section 1557 of the Affordable Care Act (ACA). ICER ignores this clear precedent and continues to use this discriminatory metric in its value assessment models. The QALY inherently discriminates against older individuals, and this specific model for assessing value of treatments for COVID-19 exacerbates these fundamental flaws as increased age reduces the value of treatment. This model also goes a step further by, in fact, sending the message that there may be more value in people dying since it associates the remaining lifetime of medical costs with saving lives. Stated plainly, this type of modeling conveys the message that there may actually be less value in the saving the life of an older person with chronic conditions than in letting them die.

This cost effectiveness model ignores crucial benefits to patients and society. Many of us have consistently shared with ICER our concerns about advancing models that do not sufficiently incorporate outcomes that matter to patients and their families and societal concerns. In this case, given the toll COVID-19 is taking on our society, non-medical costs are more important than ever. These costs, like lost productivity, do not play a prominent role in ICER's modeling. It also does not recognize the benefit of treatments that may lower the fatality rate enough for society to resume normal activities, nor the stress on our health system's capacity and impact on personnel. We are particularly concerned that despite ICER's 2020 framework indicating that ICER would begin incorporating the societal perspective in the base case of its analyses, ICER chose to omit it from this report even with the huge burden COVID-19 is putting on the nation beyond direct medical costs.

ICER's models are based on flawed assumptions. Moreover, the ICER model uses basic flawed inputs to determine the value of COVID-19 treatments. We question the calculation of symptom days for patients in intensive care, the daily cost for patients on a ventilator which is inconsistent with higher real-world costs, the use of flawed age ranges of patients that would be treated, and a lack of recognition that the treatment being evaluated would not be used on a large scale (only in 12% of patients). These vast flaws lead us to question whether ICER is manipulating the model for the purpose of achieving a lower value.

Therefore, we urge ICER to pause any future development of assessments related to COVID-19 and focus on partnering with stakeholders in the development of rigorous and patient-centered methodologies.

Sincerely,

American Association of People with Disabilities
ACCSES – The Voice of Disability Service Providers
Allergy & Asthma Network
Alliance for Aging Research
Allies for Independence
American Association of Kidney Patients
American Gastroenterological Association
Amyloidosis Support Groups, Inc.
Asthma and Allergy Foundation of America
Association of University Centers on Disabilities
Autistic Self Advocacy Network
Boomer Esiason Foundation
Bridge the Gap – Syngap – Education and Research Foundation
California Access Coalition
Cancer*Care*
Center for Autism and Related Disorders
Center for Public Representation
Cystic Fibrosis Research Inc.
Cure SMA
Cutaneous Lymphoma Foundation
Davis Phinney Foundation
Diabetes Patient Advocacy Coalition
Disability Policy Consortium

Disability Rights California
Easter Seals
Epilepsy Foundation
Epilepsy Foundation New England
Genetic Alliance
Global Liver Institute
Go2Foundation for Lung Cancer
Headache and Migraine Policy Forum
Heart Valve Voice US
ICAN, International Cancer Advocacy Network
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
Life Raft Group
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
MLD Foundation
National Alliance for Hispanic Health
National Alliance on Mental Illness
National Diabetes Volunteer Leadership Council
National Infusion Center Association
National Minority Quality Forum
NBIA Disorders Association
New York State Sickle Cell Advocacy Network Inc. (NYS SCAN)
Not Dead Yet
One Rare
Partnership to Fight Chronic Disease (PFCD)
Partnership to Improve Patient Care
Patients Rising Now
Powerful Patient, Inc.
Patient Services, Inc.
PXE International
The Coelho Center for Disability Law, Policy and Innovation
The Sickle Cell Foundation of Georgia, Inc.
Tuberous Sclerosis Alliance
VHL Alliance