January 28, 2019

The Honorable Alex Azar, Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Via electronic submission to https://www.healthit.gov/topic/usability-and-provider-burden/strategy-reducing-burden-relating-use-health-it-and-ehrs

Re: **Draft Strategy on Reducing Regulatory and Administrative Burden Relating to the Use of Health IT and EHRs.**

Dear Secretary Azar,

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this draft strategy in regard to its effects on those living with advanced illness.

C-TAC is a national non-partisan, not-for-profit organization dedicated to ensuring that all those living with advanced illness, especially the sickest and most vulnerable, receive comprehensive, high- quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC is made up of over 140 national and regional organizations including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others who share a common vision of improving advanced illness care in the U.S.

C-TAC's definition of advanced illness is when one or more conditions becomes serious enough that general health and functioning begin to decline, treatment may no longer lead to preferred outcomes, and care oriented toward comfort may take precedence over attempts to cure – a process that extends to the end of life and that for some individuals and their families may lead to transition to hospice.

Our comments on the following strategy/recommendation areas are as follows:

Clinical documentation
We appreciate the goal of reducing regulatory burden around documentation of patient encounters but want to point out that those with advanced illness often have complicated medical and social histories that need to be adequately reflected in such documentation. Lost in all the current check boxes is the patient's story- arguably the most important information in the clinical chart since it usually drives patient decisions and perspective. Therefore, we recommend a balance between the need for appropriate

care/documentation for people living wth advanced illness and any efforts to reduce regulatory burden so as to ensure safe and high-quality patient care.

In regard to leveraging health IT (HIT) related to the prior authorization processes, we suggest that such a process include decision support to help clinicians make the best treatment or medication decisions and, therefore, provide the best possible care. Due to the complexity of many with advanced illness, their clinicians have to manage multiple medications, treatments, and conditions and so prior authorization must be a helpful step, rather than a burdensome barrier. Clinicians tell us that the guessing game they have to play to find the "right" medication from a formulary standpoint, for instance, is not helpful, and that they would instead appreciate proactively knowing which of the available options will be covered upfront, so that they can make the best choice for their patients in a timely and efficient manner.

Finally, we would urge the ONC to continue to include patients and their family caregivers in any design efforts. Electronic health records (EHRs) must help to identify people's goals, values, and preferences so as to better align care with them. EHRs also need to ensure that patients and their surrogates have access to clinical documentation so that they are aware of its content and able to correct any errors or misunderstandings. The move to patient portals that interact with the EHR and efforts like Open Notes[i] will allow patients to more fully participate in their care. However, privacy concerns are also an issue with such participation and systems need to allow patients the option to disclose information to a clinician that they might not want shared with their families or loved ones.

Health IT Usability and the User Experience
We support the effort to reduce administrative burden since it reduces time available for direct patient care. Those with advanced illness need more, rather than less, of a clinician's time and so reducing administrative burden is important. We also suggest that the patient and family be considered among the "users" for usability and that their experience with their clinicians and HIT also be assessed and improved.

We further support harmonization as a goal but encourage the ONC to think of it more broadly than just among traditional health entities. The HITECH matching fund opportunity[ii] needs to be promoted among community agencies and resources. This will help ensure that any key social factors and determinants of health are documented and shared so as to be addressed. For this reason, community resources, along with patients and family caregivers, should also be part of the HIT design process.

EHR reporting
As noted above, we are in strong support of continuing to promote nationwide strategies that further the exchange of electronic health information to improve interoperability since care coordination is a key need of those with advanced illness. We therefore again urge the ONC to expand participation in interoperability by including community organizations and resources in such information exchanges.

Public Health Monitoring

We appreciate the benefit of electronic prescribing of controlled substances to better inform their appropriate use. However, we would note that many with advanced illness, including people with cancer, heart disease, and pulmonary illness, legitimately need and benefit from taking such controlled substances and HIT systems need to allow their prescribers to practice personalized medicine and prescribe such medications when appropriate and without barriers.

We would also suggest that public health reporting via HIT include advance directives and POLST forms since interoperable data or registries for these can help ensure that any care delivered is in line with the person's goals, values, and preferences.

Thank you for the opportunity to comment on this draft strategy. If you have any questions, please contact Marian Grant, Senior Regulatory Advisor, C-TAC, at 443-742-8872 or mgrant@thectac.org.

Sincerely,

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[i] https://www.opennotes.org
[ii] https://www.medicaid.gov/medicaid/data-and-systems/hie/federal-financial-participation/index.html