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Testimony for the Health Information Technology Policy Committee

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Thank you for inviting my input on this very important topic. I am pleased to help the Policy Committee find ways to support useful information technology across the continuum of care.

I am a geriatrician who has served thousands of elderly and disabled people through their deaths, I have been the direct caregiver for elderly family members, and I have done research and coached quality improvement affecting the well-being of persons coming to the end of their lives. I now lead the Center for Elder Care and Advanced Illness at Altarum Institute, a non-profit research and consulting company. Our mission is to help the U.S. find the strategies that can reliably support each frail elderly person to live comfortably and meaningfully at a cost that families and communities can sustain.

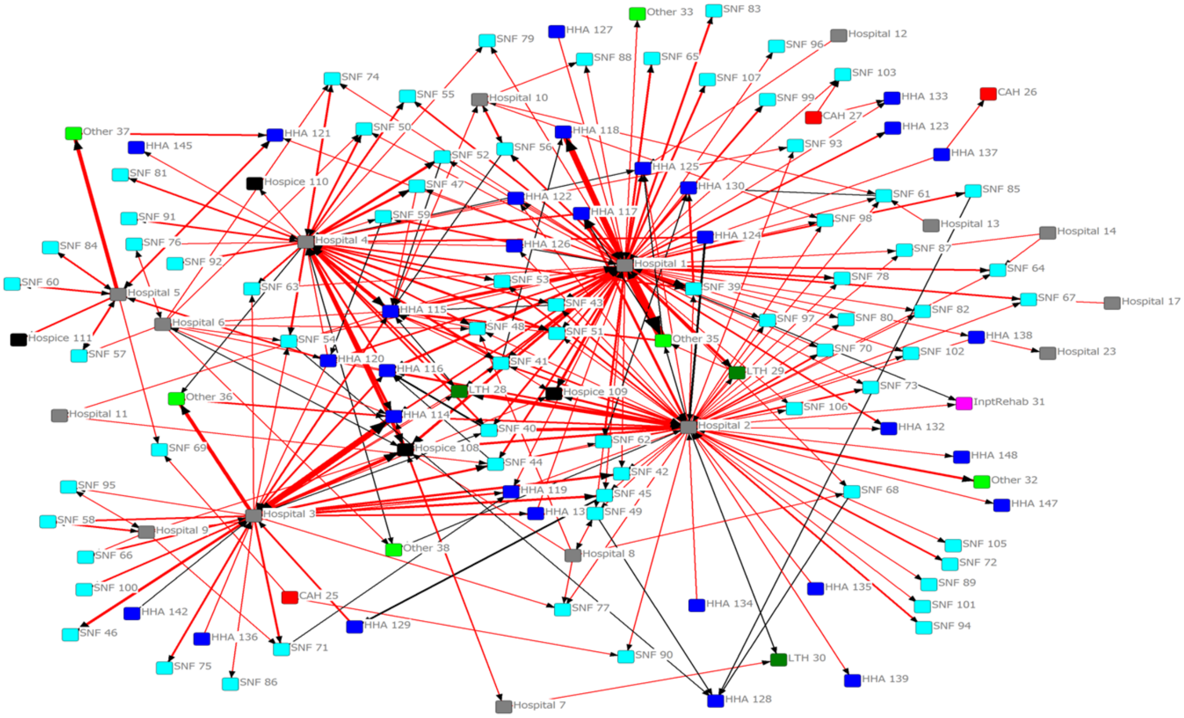
Most of us on this call will not die with a single overwhelming illness, such as metastatic cancer, stroke, sepsis, or a heart attack. Most adults now will live for many months with multiple chronic conditions and progressive disabilities in the last phase of life. For those who live to age 65, self-care disability in the life remaining now averages 3 years. For those who live to age 85, half will have progressive cognitive failure as part of the course. Fifty years ago, when Medicare was started, frailty and dementia in old age were still uncommon: the average age at death was just 68 years, and even those few who lived into old age were not considered appropriate recipients of most medical procedures. Now, for most Americans, probably half of the life-time costs of health care, including long-term supports and services, are concentrated in the period of living with eventually fatal chronic diseases and disabilities. Yet, our processes and habits are still built on the assumptions of half a century ago, when we built a reimbursement system around the priorities of what is now “middle age.” The time has come to make it possible to adapt the care system to the current realities.

When you and I go through our period of frailty in our advanced years, we will need honest information as to what we face and how various strategies of health care and supportive services will affect us and our families. We will need to organize decisions about supports and treatments into a coherent and practical plan of care. We will, from time to time, need to use a hospital, mostly when we have a “predictable crisis with unpredictable timing,” which is how geriatrics clinicians see worsening of chronic conditions and the advent of additional acute challenges. In a very real sense, hospitalization in this part of life is mostly the failure mode in chronic care – when the established plan of care is overwhelmed by a new stress or a shortcoming in implementation. Hospitalization is not the central story of the person’s life; rather, the central story is the ongoing life lived with multiple challenges, in which hospitalization plays a role. And the main role of both health care and long-term services and supports is to assist the affected person and the family to live as well and as fully as possible, pursuing their own priorities, through this period of life.

This characterization leads to a set of priorities for information technology.

1. Of course we need to have records and care plans for frail elderly people that are maintained and available across settings and time. We absolutely need to have clinicians in nursing homes, home care agencies, hospices, long-term acute care hospitals, inpatient rehabilitation facilities, and psychiatric facilities able to see records of the person's situation, goals, and plans, and able to contribute their observations and revisions as time and the situation changes. Characterization of the person's situation and the care plan needs to come into the hospital or physician's office with the person, have whatever modifications are needed, and seamlessly move back to these other settings. The person's situation and care plan attach to the person, not the setting. This requires full standardization of digitizable record elements and also the ability to carry some narrative elements that are not usefully reducible to simple data elements. It also requires some combination of full interoperability of record systems housed by different providers, effective access to record systems maintained by one provider, or a shared "in the cloud" solution as in some information exchange models. This is not an optional elements in an efficient and trustworthy care system; without it, serious errors and suffering are commonplace, and costs escalate as unwanted, unwarranted, or simply error-induced medical interventions are used.

2. The records and care plans need to support availability of patient information across a geographic area. People who are this sick and disabled use multiple providers over time (see attached transfer diagram for 10 or more annual transfers of FFS Medicare beneficiaries in Cincinnati). It is foolish to hope that special relationships involving one hospital making its records available to preferred nursing homes and home care agencies will be enough to secure continuity of patient-centered information and the care plan for most elderly people.



3. The records and care plans need to evolve so they prioritize to include some elements routinely overlooked in hospitals: the home situation, caregivers and their capabilities and appropriateness,

transportation, housing, food, safety, personal and family priorities, the likely outcomes (the life to be lived) with various choices, and the comprehensive care plan. The usual hospital record does not even include a report of the patient's function – before hospitalization, during, or predicted in the future. Indeed, all of what we have done in electronic records so far is really historical, documenting the information about the patient's past. What most matters to the patient is his or her future, and we need to make room to record goals, priorities, strategies to pursue those goals, and likely effects on the life to be lived. This is the very heart of being "patient-centered," to respond to what is most important to the patient, or more broadly, the affected person. Exceedingly few patients prioritize their lab values as goals: most have goals that involve relationships with other people or with their spiritual life, activities that they value, or actions that are important. These are the "magnetic north" that our care provision compasses need to guide services, but we don't even generally write them down, and we don't have ways to transition those insights across settings, providers, and time.

4. The records for persons living with serious illnesses and disabilities in the community must come to have documentation of the array of supports that they are relying upon. In a hospital or nursing home, supports for housing, food, medication management, caregiver support, and many other elements are built-in and need not be specified in most instances. However, most frail and disabled persons live most of the time in the community. Housing, transportation, nutrition, personal care, caregiver capabilities, finances, and similar issues become very important. Hospital and even physician records often do not really need to deal with these, and persons who will live all of short lives in facilities also probably do not generally need to address these specifically. But people living with many challenges in home settings do need specific services, and those need to be planned as part of the care plan. Thus, the usual medical record needs expansion in these domains.

5. All providers maintaining electronic record systems that serve persons with long-term service needs should have tested feedback loops among providers serving any one patient and among providers who regularly serve one another's patients. These feedback loops should provide fuel for improving records and care. Survey and certification of providers should test the transition of records and care plans across settings.

6. There is a special use for care plans for a geographic area, once they are electronic and managed in a way that makes them available centrally. They could be aggregated and used to monitor the supply and distribution of services. One could see directly how many people need physician services at home and where they are, or how many people in the area actually need nursing home care and whether the area has oversupply induced overuse or unmet needs.

So – what should ONC and CMS do with regard to providers in long-term and after-hospital care?

1. Establish standards and incentives to help long-term services providers adapt their existing EHR system or purchase a new one that meets requirements for interoperability, transfer of information, and enabling of monitoring for quality. All substantial providers of services across the continuum need to provide interoperable records or to have access to a system operated by another entity that serves the same function. That goal may require a few years, but it should be articulated as a goal.

2. Provide additional elements in longitudinal records for persons with long-term care needs, such as the content of advance directives, the services needed for the caregiver, social and environmental supports provided or needed, the likely course, the time set for re-evaluation of the care plan, and the care plan itself.

3. Standard elements should replace any non-standard items in MDS, OASIS, and other reporting systems.

4. Provide demonstrations of "in the cloud" shared systems, health information exchanges, or interoperability of records IN A GEOGRAPHIC AREA to provide transmission of important historical data along with care plans, prognosis, and advance directives (designation of a surrogate or specific instructions)

5. Incentivize regional solutions as identified in #2.

6. Learn to document a negotiated care plan in a layered record with appropriate presentation layers for different users, including the patient.

In sum, most care for persons needing long-term supports is provided by "non-eligible providers," using systems that cannot communicate with other systems, while they provide most of the care that these individuals receive. This situation ensures that ad hoc treatment decisions that ignore the patient's goals and priorities and fail to be integrated into an overall care plan will continue to be a burdensome and costly risk for people living with serious and disabling conditions – unless we create the commitment and the methods to address the problem. I hope the Committee will take on that challenge.