April 8, 2014

RESPONSE TO
Request for Information: Transforming Clinical Practices
Centers for Medicare and Medicaid Services (CMS)
Department of Health and Human Services

SUBMITTED ONLINE VIA
http://www.healthcarecommunities.org/Home/RFI-TransformingClinicalPractice.aspx

Section I. Demographic Information

Organization Type: Other; 501(c)(3) Non-Profit Research Organization
Organization Name: National Alliance for Caregiving
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Please include summary of POC’s experience related to practice transformation. Clinical Practices must identify themselves as specialty, primary care or mixed (including both primary and specialty). Clinical Practices are required to also provide practice size including number of providers and size of patient population.

The National Alliance for Caregiving is a non-profit coalition of over 50 national organizations with an interest in advancing family caregiving through research, innovation, and advocacy. Our membership includes for-profit, not-for-profit, and government organizations that work with patients and their family caregivers. Our mission includes fostering new research on the challenges faced by the 36.5 million households that support patients with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and even complex medical care. In addition to research, we also work with our members, state and local family caregiving

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coalitions, and international organizations to identify supports for family caregivers and increase awareness of the needs facing this population. As an expert in patient-centered care, the Alliance’s founding President and Chief Executive Office Gail Hunt also serves on the Governing Board of the Patient-Centered Outcomes Research Institute (PCORI).

Section III.

A. Practice Transformation Strategies, Resources and Opportunities

Question 1. Based on your organization’s experience and understanding, what does a transformed clinical practice look like?

A transformed clinical practice prioritizes shared decision making between the physician and medical team, the patient, and the patient’s family caregivers. For many patients, the family caregiver is on the front line of care, assisting the patient with the management of chronic disease. This is especially true for older patients who are struggling with Alzheimer’s or other related dementias. The Alzheimer’s Association 2013 Facts and Figures Report found that 15.5 million family and friends supported patients who are managing Alzheimer’s and other dementias. For these patients, it is critical to involve the family caregiver because the patient is often incapable of managing care on their own due to their disease.

A transformed clinical practice would do the following to support the family caregivers: (1) assess the willingness and ability of the patient-designated caregiver to perform tasks expected of them in the patient’s treatment plan; (2) include the family caregiver in shared decision making between the patient, doctor, and family (where appropriate based on the assessment); and (3) provide support to the caregiver and patient that enables them to meet the care plan’s goals.

Following an assessment of caregiver readiness and ability, the clinical practice should note the caregiver in the patient’s medical record (electronic and hard copy) and explain the goals of the patient’s care plan. The practice team should also provide instructions to the caregiver on how to assist with the patient’s care at home. Finally, the clinical practice should provide referrals to home- and community-based services that can provide additional supports for the patient (e.g., Meals on Wheels, local Alzheimer’s Association). It would also be beneficial to provide the caregiver with referrals to caregiving supports in the community, such as respite services.

Question 9. What should CMS consider as it relates to beneficiary and caregiver experience of care when practices transform?

Many family caregivers are overwhelmed at the challenges they face in helping their loved ones manage multiple illnesses and/or chronic diseases. In transforming clinical practice, CMS should encourage physicians and specialists to: (1) assess the caregiver’s ability and willingness to provide assistance to the patient, with appropriate referrals; (2) provide better measurement of
caregiver and patient satisfaction and self-reported outcomes; and (3) improve online access to patient information.

As news models of home- and community-based care increasingly rely on family caregivers, clinical practices should first identify and assess whether the caregiver is willing and able to help. For example, a caregiver may assist a patient with wound care. Because most family caregivers are not medically trained, both the caregiver and the patient may be concerned about the ability of the caregiver to manage this task at home. Assessment identifies whether the caregiver is equipped to assist with patient needs, and if not, allows the medical team to refer the patient to medically appropriate care.

Second, we would ask that CMS prioritize the development and collection of patient- and caregiver-reported outcomes in addition to experience of care data. The HCAHPS program for hospitals and the HHCAHPS program for home health patients offer models for data collection.

Finally, we encourage CMS to continue to identify ways to leverage Health Information Technology ("HIT") as a tool that family caregivers can use to help patients. The Dept. of Veterans Affairs has found new ways to help families access patient information, through its Blue Button program and the Family Caregiver Pilot which equips caregivers with iPads to help manage care. We would urge CMS to look towards these VA programs as an example of how to transform clinical practice to better support patients and their caregivers and reduce overall health system costs.

**Question 13: How are practices using Health Information Technology (HIT) and Electronic Medical Record (EMR) technology to improve patient health outcomes? How have various organizations supported HIT integration in practice transformation?**

For patients using multiple healthcare providers, HIT can improve cross-setting coordination and reduce unnecessary, duplicative treatment (or even harmful over-prescribing of medications). Effective clinical practices are using HIT that helps caregivers and families meet care plan goals.

Our research has shown that many family caregivers would benefit from the better clinical use of health IT tools. In 2011, Alliance research with UnitedHealthcare revealed that: more than three fourths of survey caregiver respondents believed that HIT tools would save time; make care easier logistically; and make care recipients feel safer. Caregivers were particularly interested in three types of HIT tools: (1) personal health record tracking programs (like the VA’s Blue Button program); (2) caregiving coordination systems that share information about physician appointments or other available resources; and (3) a medication support system to help the caregiver with medication management.

Essentially, HIT-enabled clinical practices could provide a cost-effective, efficient means of fostering shared decision making between the medical team, the patient, and the family caregiver. Under the Meaningful Use program, the Continuity of Care Document ("CCD")
provides a foundation for Electronic Health Records (“EHRs”) and EMRs used by hospitals and physicians. The CCD requires that the data be in a format easily read by a standard web browser, which creates an opportunity to offer EMRs to patients and their caregivers. Stage 3 of Meaningful Use explicitly includes family caregivers.

Including caregivers in the clinical practice’s EMRs and EHRs will support seamless patient transitions across care settings. Patients and caregivers should be given an opportunity not only to review the data in the EMRs, but also to provide corrections and offer additional information as necessary to improve communication with the medical team.

**B. Challenges and Lessons Learned in Practice Transformation Engagement**

**Question 21.** What information privacy challenges are anticipated or have been experienced in the transformation of practices? How have these challenges been addressed? What specific local, state or federal requirements presented these obstacles?

Because HIPAA requirements are often misunderstood by providers and patients alike, we would ask CMS to provide additional guidance on how family caregivers can support patients without violating the HIPAA’s goals.

Many patients may not be fully aware how HIPAA restricts informal family caregivers from accessing medical information (even if the patient wishes to include the family caregiver in health decisions). For example, while the HIPAA Privacy Rule does permit patients to identify a Personal Representative to act on the patient’s behalf in making health decisions, the personal representative is strictly defined. Personal Representatives must be legally designated by a patient or a court of law. This is an area where information could be clearer, including how the HIPAA Privacy Rule works with medical planning tools such as a Durable Power of Attorney or advanced care directive. Clinical practice teams have an opportunity to educate patients on HIPAA protections.

Additionally, many health care providers have misinterpreted or misapplied HIPAA to prevent communication with family caregivers who are not designated as Personal Representatives. It is important to note that the term “family caregivers” can include any family member or friend who is providing assistance to a patient on a volunteer basis. In fact, HHS’s Office of Civil Rights has interpreted HIPAA to permit the sharing of information that is “directly relevant” with the “spouse, family members, friends, or other persons identified by a patient, in the patient’s care or payment for health care.” (See 45 CFR 164.510(b)). Even so, many providers are not aware of this interpretation and use HIPAA to prevent communications with the family caregiver.

We would urge CMS to better educate clinical practices on HIPAA’s restrictions. The patient’s designation of a family caregiver should allow the caregiver to access appropriate health information about the patient in order to meet the goals of care.