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MEANINGFUL USE WORKGROUP

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“INCORPORATING PATIENT-GENERATED DATA IN MEANINGFUL USE OF HIT”

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Good morning, Chairmen Tang and Hripesak. I am Carol Raphael, President and Chief Executive Officer of Visiting Nurse Service of New York (VNSNY). I want to thank you, the ONC, and your colleagues for the opportunity to present testimony today to the Meaningful Use Workgroup. I am pleased that you are focused on how to include patient-generated data in the criteria for meaningful use of electronic health records and how to ensure HIT truly involves patients and families in improving how health care is delivered and experienced in the nation. Before I discuss the HIT initiatives underway at VNSNY and our perspective on patient/consumer engagement in health and health care through meaningful use of HIT and information sharing, I would like to provide some background information on Visiting Nurse Service of New York (VNSNY).

Overview of Visiting Nurse Service of New York

Founded in 1893 by Lillian D. Wald, Visiting Nurse Service of New York (VNSNY) is the largest non-profit home health care agency in the U.S.. On any given day, there are, on average, 30,000 patients in the New York City metropolitan area who are actively under the care of our workforce of 14,000 professional and paraprofessional staff, which includes 2,600 nurses, 500 rehabilitation therapists, 600 social workers, and 7,800 home health aides.

We serve a substantial number of Medicare, Medicaid and dually-eligible patients who:

- Are socio-economically diverse, reflecting the many cultures and neighborhoods in our service areas – for example, more than 36% of our patients speak languages other than English in the home (such as Spanish, Cantonese, Korean, Creole, and Ukrainian) and more than half identify themselves as belonging to a minority race or ethnic group;
- Frequently have multiple co-occurring medical diagnoses that are chronic in nature, and must be managed for life – for example, the average home care patient at VNSNY is 75 years old, has four to five co-occurring diagnoses, requires assistance with ambulation and dressing, and takes nine different prescription medications; we also provide care to at-risk or very ill children (ranging in age from newborn to adolescence), some with life-limiting diagnoses, and adults with severe disabilities, mental disorders, and drug use problems.

The goal of VNSNY's programs is to prevent illness and deterioration in symptoms and reduce avoidable hospitalizations by:

- Coordinating and managing care across settings, providers, and disciplines;
- Making transitions between settings safer; and
- Establishing a home-based source of primary care for the segment of patients whose conditions prevent them from effectively utilizing primary care in outpatient settings.

Our services include short- and long-term in-home skilled care, end-of-life care through hospice and palliative care services, home- and school-based programs for thousands of at-

risk children and their parents, and behavioral health and drug treatment programs for severely and persistently mental ill adults. We also provide comprehensive care management for both short- and long-term care needs through our VNS CHOICE health plans, which include a Medicaid Managed Long-term Care plan as well as Medicare Advantage plans for dual- and single-eligible individuals.

Last, but not least, we remain strongly committed to helping all New Yorkers in need, regardless of ability to pay. In 2009, we provided \$24 million in community benefit, nearly half of which funded direct care delivery to uninsured or underinsured patients.

Technology and Patient Care at VNSNY

A critical enabler of VNSNY's ability to manage complex patients across a continuum of care, services, and settings is the IT infrastructure we have invested in and developed over the past several years. Our investment reflects a long-held belief that the effective use of health IT can transform healthcare delivery and facilitate patient self-management. As a result, many of our efforts closely track the "meaningful use" principles being developed at the federal level.

At VNSNY, HIT enables clinicians to better manage patients by providing real-time, actionable data to inform ongoing care; identify high-risk patients for targeted interventions; and integrate care across disciplines and settings, through data sharing and communication.

In the field, all VNSNY nurses, rehabilitation therapists, and social workers use portable laptops equipped with the proprietary Patient Care Record Suite (PCRS), a structured EHR. Each clinician involved in the care of a patient uses PCRS to document the initial comprehensive patient assessment, the plan of care (built on evidence-based, diagnosis-specific treatment guidelines), and progress and milestones. While in the field, clinicians are able to retrieve up-to-date data for all patients on their caseloads, at the point of care. These data guide decision-making during visits, and are also used in the aggregate by VNSNY for outcomes analysis and quality improvement. A secure, internal website provides real-time reports to clinical managers on utilization, clinical indicators, quality scorecard measures, and patient satisfaction. These reports serve as a basis for managers to provide actionable feedback and foster continuous quality improvement.

What is the role of patient-generated data in improving health of individuals? What is the evidence?

An illustrative example of how VNSNY uses HIT and patient-generated data to achieve positive health outcomes is its efforts to improve the safety of transitions from hospital to home and reduce preventable and costly hospital admissions.

As defined by Eric Coleman, MD, and Mary Naylor, PhD, RN, "transitional care" is a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care in the same location (among multiple providers). Among other aspects, transitional care places strong emphasis on engaging the patient and family members in all aspects of care.

At VNSNY, after a patient is referred for home care service but before discharge from the hospital, VNSNY intake staff check for accurate patient information, such as the reason for hospitalization, the patient's physician in the community, and a complete list of discharge medications. The patient's EHR at VNSNY is established with this data, even before provision of home care begins. At the first in-home visit, the VNSNY nurse conducts a comprehensive clinical assessment that includes the mandated standard OASIS measures as well as questions and observations about all over-the-counter and prescription medications present in the household, the availability of family and social supports, and the physical environment and home safety. **The nurse also directly asks the patient to state the reason for the recent hospitalization or need for home care, and the patient's goals for care. The answers, as stated by patients in their own words, are entered into PCRS.** This helps the clinician understand the patient perspective on his or her own illness and informs how the clinician approaches and plans care for the patient in order to achieve the best possible outcome.

The VNSNY nurse then interactively reviews with the patient all medications s/he is taking to simplify the regimen, if possible, and eliminate potential interactions. The nurse also ensures that the patient understands the purpose and instructions for each medication. The list of medications the patient is currently taking is cross-referenced with a medications database embedded in PCRS, which detects possible dangerous interactions or complications. If necessary, the nurse will contact the patient's physician to revise the regimen and ensure that the patient clearly understands any changes. In the next few months, the nurse will also have the ability to leave with the patient a printed copy of information for every medication on the patient's regimen.

At every visit, the nurse educates and coaches both the patient and family caregivers on the current treatment plan, symptom management, and specific actions to take, through a function in PCRS called "My Action Plan." Interactive, didactic software allows the nurse to step the patient and caregivers through an animated lesson on how to manage his or her health for a given disease or condition and ends with a quiz that the patient completes on the laptop to confirm that s/he has mastered the content. If relevant, the nurse will display simple charts and graphs that track important indicators, such as blood pressure and blood glucose levels, so that the patient and caregivers can view progress throughout treatment.

Within the first two weeks after hospital discharge, the nurse will also make sure that a follow-up appointment with the patient's primary care provider in the community has been scheduled. **Prior to this physician appointment, the nurse prepares the patient by generating a complete medication record and listing symptoms, key statistics, progress indicators, and suggested questions for the doctor – all of which the patient can bring to the appointment.**

This effort to improve the transition from hospital to home depends on information sharing across and within settings (hospital, home, physician office or outpatient clinic) and involves multiple disciplines (primary care doctors, specialists, hospitalists, nurses, rehab therapists, home health aides, family caregivers). Likewise, engaging the patient and family caregivers in managing the patient's health is critical for the care to be

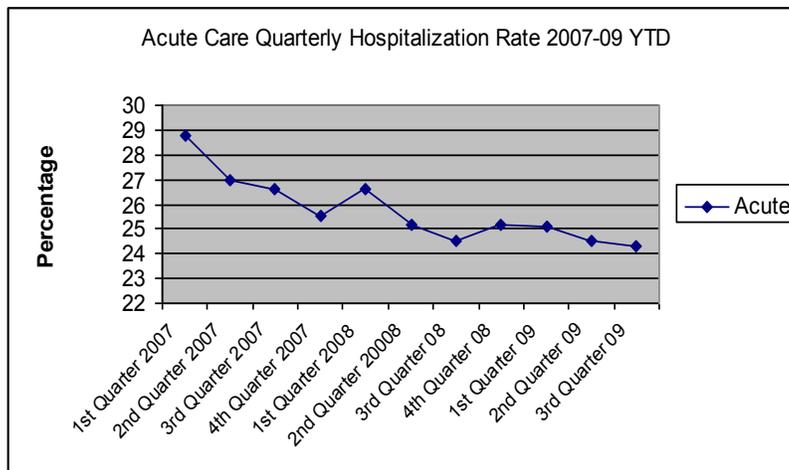
effective, in particular when the patient is being treated for an acute exacerbation of a chronic condition. The 2008 IOM report, *Retooling for an Aging America*, recognized family caregivers as key members of the health care workforce. The report found that an estimated 29 million to 52 million family caregivers (as much as 31% of the U.S. adult population) provide 20 to 25 hours per week of assistance of varying intensity, and that they were not adequately prepared to manage the patient’s transitions back home, provide ongoing care, or tap into available community resources, care options, and financing or insurance. **As the number of family caregivers is expected to increase in the future, the IOM concluded that the role of family caregivers must be integrated with the formal care system and the invaluable patient information they provide should be incorporated when the clinician plans and delivers care.**

HIT at VNSNY serves as a means to integrate information across providers involved in a patient’s care, and is also a tool for engaging and educating the patient about self-management of symptoms and illnesses. It also enables the VNSNY nurse to act as the coordinator of care for the most complex and highest-cost patients, older adults living with multiple chronic conditions who lack a regular primary care provider.

As a result of our transitional care protocol, hospitalizations for patients in our Certified Home Health Agency have declined from 29% in 2007 to 24% in 2009.



Hospitalization Rate: CHHA Acute



A second example of how patient-generated data can improve health outcomes comes from VNSNY’s involvement in the exchange of clinical data for shared patients with other provider organizations.

As a stakeholder in multiple New York State grant-funded projects, VNSNY is actively involved in establishing exchange of health data, for shared patients, with hospitals, physicians, and outpatient clinics. The goal of these exchanges is to foster collaboration

among providers in order to better manage and coordinate care for patients, particularly those with multiple chronic conditions, based on the concept of the Patient-Centered Medical Home. With the patient's opt-in written consent, we make a subset of patient data – including demographics, diagnoses, procedures, encounters, lab results, medications, allergies, and radiology and other diagnostic test results – available to his or her other healthcare providers outside of VNSNY by depositing it in the four Regional Health Information Organizations, or RHIOs, that service New York City. RHIOs serve as a hub for the shared data to be secured, warehoused, standardized, and ready to be accessed by provider members. There is evidence that VNSNY's patients see value in these exchanges: Ninety per cent have actively opted in to having their data be included in the exchange, and to date we have provided RHIOs with information corresponding to more than 90,000 patients.

We also help patients and their physicians manage care through our MD web portal. Currently, 200 physicians are using this portal, and our goal is to increase this number to 650 by the end of 2010. After the initial assessment and in-home visit, the VNSNY nurse, with the participation of the patient and caregivers, creates a plan of care and enters it into PCRS (the VNSNY EHR). *For patients whose primary care physicians use the MD web portal*, the VNSNY system then generates a notification to the patient's primary care physician that there is a plan of care for one of their patients that requires their review and revision, if necessary. Once the physician has approved the plan of care, he or she electronically signs the order, and this signature is stored and becomes part of the patient record. This eliminates the need for manual paper handling between providers, while adhering to HIPAA privacy and security standards and complying with regulatory requirements.

How can patient-reported data be integrated into EHRs and the clinicians' workflow to improve care management?

Patient-reported data can be integrated into EHRs through software that allows the nurse to enter the patient's responses to open-ended questions such as "Why were you in the hospital?" and "What goal do you have for your health?" The answers in the patient's own words often are very different from the information provided by clinicians or extracted from medical records, and shed light on the patient's health literacy and readiness to play a role in his or her own recovery. For example, a typical patient goal is "To be well enough to go to my granddaughter's wedding in June," or "To walk to the grocery store without having to stop along the way." Involving the patient from the outset in setting goals and outlining an action plan is important in helping the patient adhere to the treatment regimen and regain health or functioning. Ongoing feedback to patients through progress tracking is also critical so that patients and caregivers recognize milestones that have been achieved and feel motivated to continue working toward symptom management and recovery.

At VNSNY, clinicians enter such patient-generated data into the PCRS EHR, where it then becomes accessible and available to *all* VNSNY clinicians caring for the patient as a matter of course. Clinicians can add to and refresh the record in the field, during home visits, to get a real-time snapshot of the patient's progress and symptoms.

VNSNY is now piloting a direct, reciprocal exchange of clinical data between PCRS and the GE Centricity EHR of a large primary care practice in Manhattan. This means that

information on shared patients that is entered by VNSNY clinicians into PCRS populates the GE Centricity record in the physician practice, in a manner that seamlessly occurs in the background and does not disrupt the usual workflow of the physician. The data shared in this direct exchange includes patient identification and demographic data (date of birth, address, phone numbers, family members, insurance, etc.), clinical data (diagnoses and problem lists, medications, results of diagnostic tests, assessment of the patient's condition), treatment goals, and specific treatment orders. This exchange also allows the physician and VNSNY clinician to send free-form messages to communicate non-emergent information that may be relevant to the course of home care treatment.

How can future conceptions of personal health information platforms and information tools facilitate patient-centered care, including transparency, coordinated care, patient activation, while protecting patient privacy?

We believe that one key way for future conceptions of personal HIT platforms and tools to facilitate patient-centered care is to better engage patients and encourage adoption and active use of Patient Health Record (PHR) programs by contributing and updating clinical data on an ongoing, regular basis. This can be achieved if the PHR:

- Allows a patient-designated caregiver or family member to enter data on the patient's behalf, assuming the caregiver or family member has the appropriate credentials to enter the secure PHR system;
- Incorporates features and functions that patients and caregivers find useful, therefore encouraging both adoption as well as consistent use of the PHR; and
- Adheres to all privacy and security requirements of HIPAA and other regulations.

VNSNY has been active in shaping and implementing standards for privacy, security, and consent, in New York State and nationally.

We are now exploring whether some patients and/or their designated family members or caregivers are interested in maintaining a PHR, which would include not only the data entered by VNSNY clinicians but also any data that their other providers supply, and patient-entered data. Initial discussions with patients and nurses in our long-term care programs suggest that some patients in those programs may be interested in using this type of PHR and that it may help them to manage their health.

What is the role of the patient in ensuring data in EHRs is accurate?

The ARRA requires that as of February 17, 2010, healthcare providers with EHRs must provide the patient with an electronic copy of their record if the patient requests it. VNSNY has developed software to comply with this requirement. To date, no patients have requested their record, but we expect that as more patients start to use PHRs, more will ask their providers to send electronic copies of their health records so that the patient can incorporate records from multiple providers into his or her single PHR and review the aggregate health record for accuracy. Patients and their caregivers must share in the responsibility of ensuring

accuracy by actively reviewing their health records and taking steps to communicate concerns with their providers.

What are your recommendations for meaningful use criteria for 2013 and 2015 that are achievable by a broad spectrum of providers?

1. **We recommend that the meaningful use criteria for 2013 require that eligible, participating physicians and hospitals electronically exchange data, either directly or through regional health information exchanges, with home care providers and nursing homes in their communities** who already employ EHRs that conform to all security, privacy, and data standards.

A large proportion of patients discharged from acute care hospitals then receive care from a post-acute care provider, such as a home health agency or skilled nursing facility. Post-acute care providers are often in the best position to observe the real-life needs of and challenges faced by the patient in the community, and assess the patient's readiness and ability to engage in his or her own care. For example, the home care provider is the only entity that can directly observe the patient's physical environment, all over-the-counter and prescription medications in the home, the patient's diet, and social and economic factors that can significantly impact how quickly and successfully a person is able to regain function after an acute episode.

While physicians and hospitals are eligible for federal financial incentives and reimbursement for meaningful use of certified EHRs, VNSNY, as a post-acute and long-term care provider, currently is not eligible for these incentives or reimbursement. Nevertheless, we believe that post-acute and long-term care providers play a significant role in the patient's recovery from hospitalization and ability to avoid costly rehospitalizations. Therefore, clinical data from entities like VNSNY is critical to effectively coordinate care, particularly for patients whose treatment goal is not "cure" but rather, "maintenance of function and prevention of decline."

2. **We recommend that EHRs be designed to assist healthcare providers in recording the information they receive from patients.** In particular, all certified EHR software should be required to allow clinicians to enter open-ended and subjective answers, provided by patients and key caregivers, to health-related questions.
3. **We recommend that EHRs be designed, from the outset, to maximize a clinician's ability to engage, educate, and empower patients and family members to play an active role in the patient's recovery,** prevention of decline, management of symptoms, and regaining of function. The definition of "patient" in the unit of care should be expanded to include family caregivers, who increasingly are filling gaps to compensate for workforce shortages and inadequate funding for long-term supports in the formal care system.
4. **We recommend that meaningful use criteria include a requirement that eligible, participating providers regularly assess their patients' experiences with the care delivered by the clinician equipped with an EHR.** Patient self-management of health

depends on the ability of the clinician to provide information and feedback to the patient and caregivers that is understandable and actionable. As stated above, we recommend that vendors design EHRs from the outset with the idea that it must enable clinicians to better engage and empower patients and family members to play an active role in achieving treatment goals. However, no design principle can replace actual feedback from the patient – the person whom EHRs should *ultimately* benefit – regarding his or her experience during care provision. For example, the patient should never feel as if a computerized system is replacing or diminishing the quality of the face-to-face, human interaction between patient and the clinician. For this reason, we recommend that “meaningful use” require providers to incorporate and act on patient feedback on the EHR-augmented clinical care experience.