January 14, 2013

Farzad Mostashari, MD
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

RE: Request for Comment Regarding the Stage 3 Definition of Meaningful Use of Electronic Health Records (EHRs)

Dear Dr. Mostashari:

The Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to respond to the HIT Policy Committee's request for comment regarding the Stage 3 Definition of Meaningful Use of Electronic Health Records (EHRs). DREDF is a leading national law and policy center that works to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. We are committed to eliminating barriers and increasing access to effective healthcare for people with disabilities and eliminating long-overlooked health disparities that affect the length and quality of their lives. Our comments below will refer to the objective identification number provided in the document whenever applicable.

Objective SGRP 104

We appreciate how much HITPC needs to consult and synchronize its disability-related efforts with critical federal entities such as the CDC, NCBDDD, and NCHS, but feel that that there are some clear suggestions that can be recommended for immediate action. We strongly agree that the collection of disability status must differentiate between what patients report with regard to functional impairment and their related reasonable accommodation needs/preferences (e.g., American Sign Language interpretation, Braille or large font, mechanical lifts or transfer assistance, extended appointment times, and so forth), and the medical diagnoses and labels that are clinically determined and placed on a patient's record by health care providers. Unfortunately, this suggestion appears to be placed among a demographics objective that will potentially be retired because more than 80% of unique patients already have their sex, race, ethnicity, date of birth, etc. recorded. Clearly, 80% of patients do **not** have their disability status recorded, in terms of their functional impairment and accommodation needs, and a disability status objective to capture this information cannot be retired since it has never been required.

Our recommendations with regard to the demographics objective are therefore:

- Require eligible providers and hospitals to formalize, through established forms and procedures, the collection of information voluntarily obtained from patients, or with the

assistance of their chosen authorized representatives, concerning their functional impairment status and accommodation needs, *distinct* from their medical diagnosis or condition(s);

- Require eligible providers and hospitals to use the six American Community Survey (ACS) questions to obtain data from patients concerning their functional impairments[1] (see below);
- Require EHRs to have the capacity to add additional questions for eligible providers and hospitals as necessary to capture both information concerning the reasonable accommodation or assistance needs that people with disabilities have relating to health care delivery, and individuals with functional impairments that may not otherwise be recognized through the six existing ACS questions[2];

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[1] Six questions asking about functional limitations have now been incorporated into the ACS following cognitive testing and non-response assessment. These six questions are used to identify respondents with disabilities in the ACS and several other federal surveys. Thus, there is increasing consistency in the use of a set of questions to identify the population of persons with disability. The six questions in the American Community Survey (2008 version and subsequent) are:

1) Is this person deaf or does he/she have serious difficulty hearing? (17a: Hearing Disability, asked of all ages)
2) Is this person or does he/she have serious difficulty seeing even when wearing glasses? (17b: Visual Disability, asked of all ages):
3) Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? (18a: Cognitive Disability, asked of persons ages 5 or older)
4) Does this person have serious difficulty walking or climbing stairs? (18b: Ambulatory Disability, asked of persons ages 5 or older)
5) Does this person have difficulty dressing or bathing? (18c: Self-Care Disability, asked of persons ages 5 or older)
6) Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (19: Independent Living Disability, asked of persons ages 15 or older)

[2] DREDF has made a similar suggestion in comments submitted in August 2011 to the U.S. Department of Health and Human Services regarding new point-of-provider data collection requirements contained in Section 4302 of the Affordable Care Act. In May 2012, we submitted comments on the EHR Incentive Program Stage 2 Proposed Rule, and included the following 4 specific questions, written in the 2nd person. These exemplify the kinds of additional questions that we believe should supplement the existing six ACS questions, though we acknowledge the need for further discussion and testing among experts concerning the best way to solicit needed information.

1. Do you have a primary diagnosis that relates to a physical, mental, emotional, learning, developmental, or other limitation or impairment that is not captured in the above six questions? (For example, learning disability, autism, bi-polar disorder, intellectual disability). Y/N
a. If yes, please specify.
2. Do you use any type of assistive technology such as a wheelchair, crutches, hearing aids, electronic or manual communication device? Y/N
a. If yes, what device(s) do you use?
3. Do you require any physical accommodations such as transfer assistance, assistance positioning, and/or accessible examination equipment such as an exam table or weight scale? Y/N
a. If yes, what accommodations do you require?
4. Do you require assistance or accommodation to communicate? Y/N
a. If yes, what assistance or accommodation do you require (e.g., ASL interpreter, print materials in accessible formats such as large font or digital format, assistive listening device, additional time)?

- Consult with the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD), National Center on Health Statistics (NCHS), Disability and Health Data Systems program, consumers with disabilities, and disability advocates for guidance and ideas on further incorporating disability status into future MU stages.

These steps, just like the need to obtain information concerning preferred language, are absolutely necessary for obtaining complete patient histories that will enable individuals with disabilities and people aging with and into functional impairments to receive effective, quality health care. Information about disability, functional impairments, and needed accommodations or policy modifications should be self-reported by the person with the disability. The person with the disability may choose to use the communication assistance of an accompanying guardian, personal assistant, family member, or friend. If the person with the disability is unable to self-report, a guardian, personal assistant, family member, or friend with appropriate knowledge may provide the information. All information should be provided voluntarily.

Objective SGRP 108

We do not agree with the simple retirement of this measure. Instead, we recommend a modification of the measure that would enable flagging of that portion of the population that has consistently *not* had their height/length, weight, blood pressure (for those over 3 yrs of age), and BMI recorded as structured data, and the development of ways to track this population's characteristics such as socio-economic level, race/ethnicity, and functional impairment status (e.g., patients with mobility impairments often fail to have their current weight recorded over decades long periods, with resulting inaccuracies in medication and surgical treatments).

Objective SGRP 109

We do not agree with the simple retirement of this measure, for the same reasons and with the same recommendations that we have provided for Objective SGRP 108.

Objective SGRP 113

We have two points relating to this objective:

- We support a certification criteria that includes the capacity to flag preference-sensitive conditions and provide decision support materials for patients, but strongly advise that this must include the simultaneous requirement to record the patient's communication needs and that materials were supplied in an alternative format and/or language that meets the patient's needs. This requirement *in* the HER will do more, at a practical level, to ensure that patients with vision, hearing, or limited English proficiency receive appropriate support and involvement than a general statement that the Americans with Disabilities Act/Section 504 of the Rehabilitation Act applies.

- The Certification criteria proposed for future use distinguishes abstractly between procedures/surgeries/lab/radiology/tests that are standard for which a payer can grant prior approval in real time, and those that are non-standardized and highly

individualized, and suggests a way to create a standardized approval form with a set of medical necessity questions for the latter. We would ask that individual patient histories be included in the calculus of whether a procedure/surgery/lab/radiology/test be considered standard or not. There are individuals with certain disabilities and rarer complex conditions that may repeatedly, over time, require procedures…tests that are "non-standard" in the general population, and this fact should not mean that the patient and provider seeking approval should constantly be subject to lengthier and more complicated approval procedures and medical necessity appeals. If medical expertise and patient history establishes that a procedure…test is "standard" *in the case of a particular patient*, then it should be possible to obtain prior authorization electronically in real-time. Procedures…tests can also be considered "not standard" because of how often they are needed by a particular patient. For example, x-rays to diagnose fractures are probably a "standard" procedure, but are likely required infrequently for the "average healthy person." For people with osteogenesis imperfect, however, such, for example, frequently require x-rays to X-rays can be frequently required. In such cases, certification criteria should **not** be applied so as to place prior approval in real time out of the grasp of the provider and patient, and require them to medically justify x-rays once some threshold number of x-rays have been ordered.

Objective SGRP 115

Given the increasing recognition of health and health care disparities experienced by people with disabilities, we highly recommend that this Stage 3 recommendation include the capacity to generate lists of patients with specific functional impairments that have recognized reasonable accommodation needs, and not only lists of patients with specific conditions. The original objective is to creation near real-time, actionable reports that can be used for "quality improvement, reduction of disparities, research, or outreach reports." The capacity to create lists according to specific conditions or diagnoses will bring attention to barriers that people with disabilities commonly encounter along with people without disabilities, but it will not catch the degree to which patient care is compromised by the failure to recognize, track, and meet the physical and programmatic accommodation needs of patients with disabilities,

Objective SGRP 116

We support the Stage 3 recommendation that "more than 20%" of patients who should receive reminders for preventive/follow-up care be "sent a reminder, per patient preference." However, patients with specific communication needs such as individuals who are blind, have visual impairment, or who are Limited-English Proficient, will invariably not benefit from this objective and measure unless it is accompanied by certification criteria that requires asking and recording the patient's (or responsible family member or guardian's) communication needs. We hear from many people who are blind or have visual impairments who (1) receive reminders in standard print format; (2) do not know they have any option to receive reminders and patient information in any format other than standard print; and/or (3) have their requests for a needed alternative format such as large font print or an electronic format consistently ignored.

Objective SGRP 204A

We support the ONC's adoption of Level AA conformance with the Web Content Accessibility Guidelines (WCAG) for the next edition of certification criteria. The web is a dynamic environment that thrives on innovation and new technology. It has enormous potential for providing equal access for people with various disabilities, and equal potential to leave people with disabilities behind when innovations assume that users have unimpaired vision, hearing, mobility, or print comprehension. The ONC's requirement for the next level of WCAG conformance sends the critical message that EHR technology must be universally designed from the beginning, to maximize the system's independence, privacy, and usability for all patients/consumers.

Objective SGRP 205

The after-visit summary should include summaries of any changes in treatment regimen decided upon during the visit, any changes in regiment discussed or proposed by the provider or patient during the visit, any changes in specialty care raised by provider or patient, any care coordination or needs concerns raised by the patient, and any concerns about newly required or ongoing reasonable accommodations needed by the patient (e.g., height-adjustable table, transfer assistance, appointment remainders in electronic format or large font, etc.)

Objective SGRP 206

We strongly support this CORE measure as a first step, but also foresee that the current low 10% threshold will easily bypass all patients who have communications needs other than standard English format. The Stage 3 recommendation for non-English speakers will be beneficial to at least some of those speakers. There must also be a recommendation that requires "additional alternatives format support" which requires patient-specific education materials to be offered in alternative formats such as Braille, large font print, audio-recordings, or electronic format such as CDs. Without such a measure, thousands of patients who are blind, visually impaired, or who have print impairments, will receive education resources that they cannot comprehend.

Objective SGRP 208

This EP and EH measure should be expanded to include not only a requirement to record communication preferences for 20% of patients, but also the alternative format needs for at least 20% of patients who cannot use standard print format. The Stage 3 recommended measure presumably is included because the HITPC recognizes that meeting individual preferences for communication will result in patients paying greater attention to the contents of those messages, whether they are appointment reminders, referrals, or test results. This same reasoning applies with even greater urgency in the case of individuals who are asserting communication needs, and not mere preferences.

Objective SGRP 303

We strongly support the inclusion of the care plan elements listed for future MU stages for patients who are transitioning their site of care. Information concerning a consumer's functional status/ADLs, social and financial information, and long-term goals of care, are vital components in any individual's health care, and especially for people with disabilities and older individuals. Key questions for us in reviewing this objective are: who decides the elements that are applicable, and when is this decision made? These elements, and the questions we raise, make a very strong case on the necessity for including patient-generated and patient-reported data when it comes to quality measures. If the EHR is to play an increasingly important role in the concept of shared care planning, and then the EHR must build in the principles of patient-centered planning and consumer self-direction. One concrete example of how these principles will effect team-based care and access to the EHR is that many patients with disabilities either directly employ their non-professional Long-term services and supports (LTSS) caregivers, or are the *de facto* employers while a state agency serves as an employer of record. In those cases, the patient's needs and preferences should dictate whether the non-professional caregiver has access to the EHR, and the degree to which such caregivers should be part of the care giving team.

Moreover, the HER must have the capacity to record the patient's LTSS needs and preferences, both those indicated directly by the patient and those input by family members, friends or caregivers that are recognized by the patient as having such input. This will enable the EHR to be a tool that is useful to patients who prioritize remaining in/returning to independently living in their own communities after a hospital, rehabilitation, or respite stay, and enable recording (and needing) new care needs that arise over time. Clearly if the HITPC is prioritizing the recording of patient advance directives, they should equally prioritize the recording of a patient's goals and preferences before end-of-life decisions are required.

Objective SGRP 408

Some of the MU criteria are "first steps" toward very important goals such as increasing care coordination, achieving transparency of patient records, and decreasing disparities caused by communication and language inaccessibility. Allowing EPs/EHs to slip on achieving these objectives would place consistent and greater compliance with these goals even further away. On the other hand, it is possible to envision situations where particular EPs and HPs who are actively seeking outreach to specific disadvantaged groups may actually fall short of the MU criteria for that very reason. For example, if a provider of hospital purposely sought to increase its capacity to record and chart changes in vital signs (SGRP 108) among a population that has historically failed to have this information recorded, such as individuals who have mobility, strength, or nerve impairments, then they could, in the beginning of the initiative, potentially fall short of the 80% required threshold as the provider/hospital initiates necessary equipment, policy changes, and staff training. Such a commendable initiative should in no way be dis-incentivized because of the difficulty of achieving the specific objective and potentially falling short of the accepted measure. In such cases, the hospital or provider should be able to establish a rationale that is clearly related to the ultimate goal behind the objective, and link the initiative to any shortcomings in the measure of achievement, as well as establish a plan for improving its measure over a reasonable amount of time.

The above example could equally apply to EP/EH initiatives designed to further refine and direct their EHR toward capturing information that is important to understanding more about health disparities and the effectiveness of health care services rendered by, for example improving communications with limited English-proficient individuals, or individuals with sensory, cognitive, or developmental disabilities.

Question # QMWG05

HITPC and QMWG will not capture input from a wide variety of individual patients and consumers, and organized entities representing them, without active outreach to health consumers, people with disabilities, seniors groups, and advocacy organizations. A call for comments must be circulated on these groups' listservs, and the call must be accompanied by *a plainly-worded explanation of how and why meaningful use and EHRs will make a difference to the consumer.* This is not self-evident in the conceptual mission of the HITPC or in the calls for comment currently placed in the Federal Register and other federal publications and websites. Community-based organizations and LTSS consumers and providers can also play a role in outreach to patients, consumers, and their families and advocates.

Question #QMWG08

DREDF does not consider "EHR-enabled" to be a determining characteristic for the prior or present question. The value of EHRs, and the principles of patient-centered care and patient self-direction, are relatively new. In part, this means that the latter principles will not necessarily have been integrated into the historical and current development of EHRs. That fact alone cannot be determinative of the current necessity for integrating patient-centered care and self-direction into both EHRs and how they are used. Developing and maintaining an equal place for quality measures based on patient-reported and patient-directed data is perhaps the only way to ensure that patients have an active and meaningful voice in a health care process that is increasingly evidence-based.

Furthermore, changes initiated by the Affordable Care Act are increasingly calling for and rewarding the integration of clinical/medical care, and long-term services and supports (e.g., the Medicare and Medicaid dual eligible initiatives at the Centers for Medicare and Medicaid). At the same time, many states are looking to managed care entities as the primary means for achieving quality care and financial savings, even when those managed care entities have little experience serving a population with chronic and high health care needs. In this environment of large corporate entities and powerful cost-saving incentives, the individual consumers' voice *must* be present, and provided with a way to balance purely provider-derived clinical quality measures.

There are in fact a number of consumer-oriented, primarily outcome oriented, quality measures that have been developed In the arena of long-terms supports and services. Some of these may be EHR-enabled, and some may not. Nonetheless, in the LTSS arena that is critically important to the health, well-being, and lives of people with various disabilities and their families, there exist consumer-oriented and generated

quality measures that could potentially be used in the field of health care quality measures. DREDF has worked on a paper that examines these measures, in conjunction with the work of Professor Stephen Kaye, who has compiled an analysis of a number of survey tools and measures that solicit consumer-generated LTSS quality measures. This paper will be published online in the next few weeks, unfortunately past the deadline for these comments, but other national entities such as the National Quality Forum have been examining these issues for many years. Our prime recommendation is therefore that this set of questions be re-oriented away from a search for patient-generated and patient-oriented quality measures that are already EHR-enabled, to a search for how patient-generated and patient-oriented quality measures may be modified and developed for inclusion in EHRs.

Thank you again for this opportunity to comment on the Stage 3 Definition of Meaningful Use of Electronic Health Records (EHRs). We deeply appreciate the work of the Committee and the HITPC workgroups. DREDF especially appreciates and supports the recommendation that Stage 3 is the "time to begin to transition from a setting-specific focus to a collaborative, patient- and family-centric approach," though we must also insist that "patients" must be recognized in all the complexity of their lives and capacities, and not simply in their role as "patients."

Yours truly,

Susan Henderson
Executive Director