

June 15, 2015

By hand delivery

Acting Administrator Andy Slavitt
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

re: Proposed Amendment of Key Patient-Engagement Criteria in Stages 1 and 2 of the Medicare and Medicaid Electronic Health Record Incentive Programs, File No. CMS-3311-P

Dear Acting Administrator Slavitt,

The Consumer Partnership for eHealth (CPeH), the Consumer-Purchaser Alliance (C-P Alliance), and the undersigned 50 organizations submit these formal comments on the Centers for Medicare & Medicaid Services's (CMS) proposed reversal of key patient-engagement criteria in meaningful use for 2015 to 2017. The Consumer Partnership for eHealth is a coalition of consumer, patient and labor organizations working since 2005 at the national, state and local levels to advance electronic health information technology and exchange (health IT) in ways that measurably improve the lives of individuals and families. Led by the National Partnership for Women & Families, the combined membership of CPeH represents more than 127 million Americans. The C-P Alliance is a collaboration of leading consumer, labor, and purchaser organizations committed to improving quality and affordability of health care through the use of performance measurement to inform consumer choice, payment, and quality improvement.

CPeH, C-P Alliance, and the undersigned organizations and individuals are dismayed that CMS intends no longer to require that five percent of patients¹ view, download or transmit their health information or send a secure message to their providers. Instead, CMS proposes that doctors and hospitals merely show that *just one patient* used online access to their health information, and that secure messaging was *merely turned on*, not whether any patient has actually used it. We are deeply disappointed in CMS's reversal of these essential commitments to patient and family engagement.

¹For purposes of brevity, we refer throughout our comments to "patient" and "care," given that many federal programs and initiatives are rooted in the medical model. To some, these terms could imply a focus on episodes of illness and exclusive dependency on professionals. Any effort to improve patient and family engagement must include the use of terminology that also resonates with the numerous consumer perspectives not adequately reflected by medical model terminology. For example, people with disabilities frequently refer to themselves as "consumers" or merely "persons" (rather than patients). Similarly, the health care community uses the terminology "caregivers" and "care plans," while the independent living movement might refer to "peer support" and "integrated person-centered planning."

Current regulations require that patients and families can access their health information online in Stage 2 in order to view it, download it, share it and use it, and that patients can send secure messages to their providers. The regulations also require more than passive availability, and for good reason. As CMS itself concluded when it adopted the threshold in 2012, “we continue to believe that EPs are in a unique position to strongly influence the technologies patients use to improve their own care, including viewing, downloading, and transmitting their health information online. We believe that EPs’ ability to influence patients coupled with the low threshold of more than [5] percent of patients having viewed online, downloaded, or transmitted to a third party the patient's health information make this measure achievable for all EPs.”² CMS stated similar reasons for adopting the five percent threshold for secure messaging.³

Every available piece of survey data shows that 5 percent is more than achievable. In fact, CMS itself reports that median performance is 32 percent of patients for doctors and 11 percent of patients for hospitals on Stage 2’s measure of actual online access.⁴

According to a national survey by the National Partnership for Women & Families, of all patients who have online access, 86 percent use it, and 55 percent use it at least three times per year.⁵ A majority (56 percent) of patients want the ability to email their providers.⁶

The Department of Health and Human Services’s national initiative on delivery system reform cannot possibly succeed without active engagement of patients and family caregivers, and online access is a critical tool for so many. The more frequently individuals access their health information online, the more they report that it motivates them to do something to improve their health (71 percent for frequent users, compared with 39 percent for infrequent users).⁷ Simply offering but not engaging patients to use online access does not improve care and health. Among patients who do not use online access, 35 percent do not know that it is available, and 31 percent report that doctors never discussed the option.⁸ Online access and use of personal health information is a cornerstone of better care, smarter spending and healthier people.

²Department of Health and Human Services, Centers for Medicare & Medicaid Services, “Medicare and Medicaid Programs; Electronic Health Record Incentive Program--Stage 3,” 77 Federal Register 53968, 54009 (Sept. 4, 2012).

³Id. p. 54031.

⁴Department of Health and Human Services, Centers for Medicare & Medicaid Services, “Medicare and Medicaid Programs; Electronic Health Record Incentive Program--Stage 3,” 80 Federal Register 16732, 16756 (Mar. 30, 2015).

⁵National Partnership for Women & Families, *Engaging Patients and Families: How Consumers Value and Use Health IT*, p. 28 & chart 13 (Dec. 2014), available at <http://www.nationalpartnership.org/research-library/health-care/HIT/engaging-patients-and-families.pdf>.

⁶Id. p. 34.

⁷Id. p. 30 & chart 15.

⁸Xerox, *Annual Xerox EHR Survey: Americans Open to Viewing Test Results, Handling Healthcare Online* (Dec. 2014), available at <http://news.xerox.com/news/Xerox-EHR-survey-finds-Americans-open-to-online-records>.

CMS's proposed amendments constitute a dramatic retreat from essential efforts to make patients and family caregivers true and equal partners in improving health through shared information, understanding and decision-making. A minimum standard of 5 percent signals a genuine expectation by CMS that organizations make the process changes necessary to support online access; it is meaningful enough to drive real progress in patient and family engagement and real change in clinical culture. Dropping to just one patient, and merely turning secure messaging on, signals a drastic reversal in CMS's expectations of providers and patient engagement. We urge you *not* to adopt these two proposed amendments, to avoid the substantial harm they would cause for meaningful use and interoperability in 2015-2017, and instead to maintain the existing thresholds for both patient engagement measures.

If the Consumer Partnership for eHealth and the Consumer-Purchaser Alliance can help CMS in any way to improve the proposed regulations, or if you have any questions about these comments, please contact Mark Savage at (202) 986-2600 or MSavage@nationalpartnership.org.

Sincerely,

AARP

American Association on Health and Disability
American Cancer Society Cancer Action Network
Asian & Pacific Islander American Health Forum
Association of Asian Pacific Community Health Organizations
California Pan-Ethnic Health Network
Caregiver Action Network
Caring from a Distance
Center for Democracy & Technology
Center for Medical Consumers
Connected Health Resources
Consumers' CHECKBOOK/Center for the Study of Services
Colorado Consumer Health Initiative
Consumer Federation of America
Disability Policy Consortium
Disability Rights Education and Defense Fund (DREDF)
Families USA
Genetic Alliance
Healthwise
Health Policy Corporation of Iowa
Informed Medical Decisions Foundation
Iowa Health Buyer's Alliance
Justice in Aging
Lakeshore Foundation
Lehigh Valley Business Coalition on Healthcare
Lesbian Health Initiative (LHI)
Louisiana Housing Alliance
Maine Health Management Coalition
March of Dimes
Minnesota Health Action Group
Momentum Health Strategies
Mothers Against Medical Error
National Alliance for Caregiving

National Center for Lesbian Rights
National Center for Transgender Equality
National Consumers League
National Health Council
National Health IT Collaborative for the Underserved
National Health Law Program
National Partnership for Women & Families
Pacific Business Group on Health
PULSE of America
Service Employees International Union
St. Louis Area Business Health Coalition
Summit Health Institute for Research and Education, Inc.
The Alliance
The Children's Partnership
The Empowered Patient Coalition
United Church of Christ, OC Inc.
Wyoming Business Coalition on Health

cc: The Honorable Sylvia Matthews Burwell,
Secretary, Department of Health and Human Services
Dr. Karen DeSalvo, M.D.,
National Coordinator for Health Information Technology