Consumer Partnership for eHealth

March 31, 2015

By electronic mail

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re: Consumer Partnership for eHealth's Comments on the draft Shared Nationwide Interoperability Roadmap

Dear Dr. DeSalvo:

Thank you very much for the opportunity to provide input on the draft Shared Nationwide Interoperability Roadmap. The Consumer Partnership for eHealth (CPeH) is a coalition of consumer, patient and labor organizations working at the national, state and local levels to advance private and secure electronic health information 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. Consumers are eager to work with ONC to achieve a nationwide health ecosystem for the benefit of all Americans.

I. Individuals, Family Caregivers and Consumers as Drivers of Interoperability

We applaud the Roadmap's focus on achieving interoperability to enable and support a learning health system, in which all individuals, their families and care providers can send, receive, find and use electronic health information in a manner that is appropriate, secure, timely and reliable, and the care delivery system links with communities and societal supports to enable continuous learning and improved health. Moreover, we especially appreciate and support ONC's commitment that interoperability explicitly includes individuals, patients and families. Efforts to achieve interoperability cannot simply be done for individuals and families, but rather *with* individuals and families, and therefore, we commend ONC's integration of individuals' and families' equal role in improving interoperability and moving towards a learning health system. Better care, better health and lower cost absolutely depend upon patients' being equal and engaged partners in these efforts.[1]

II. Guiding Principles for Nationwide Interoperability

As consumer and patient advocates, we believe that health IT can engage and empower individuals and their caregivers to become more active partners in their health and care. We strongly support the guiding principle to *Empower Individuals* and agree that electronic health

[1] For 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 may refer to "peer support" and "integrated person-centered planning."

information from the care delivery system should be easily accessible to individuals. We also support ONC's guiding principle for interoperability that *One Size Does Not Fit All*, which compels innovators to investigate and design usability to meet diverse users' needs, including personal preferences. To the extent that we weave this flexibility now into the design and implementation of electronic health records (EHRs) and information exchange across the nation, we save ourselves the substantial delay and cost of retrofitting these systems later. Finally, we applaud the addition of a principle addressing *Scalability and Universal Access*, but encourage ONC to consider diversity of individual *users* as well as systems in efforts to ensure that no one is left on the other side of the digital divide.

III. A Common Clinical Data Set

ONC has rightly identified the ability for individuals and providers to send, receive, find and use a common clinical data set to improve health and health care quality as the first step needed to be achieved in 2015-2017. We greatly appreciate the inclusion of care plan fields, including goals and instructions, care team members, and notes and narrative in this data set because these data are critical pieces of information about individuals' care and health that are necessary for safe and effective transitions of care. We encourage ONC to explicitly reference family and other caregivers (name, role and contact information) as part of the care team included in the common clinical data set. Additionally, we interpret "Care plan field(s), including goals and instructions" to refer to both clinical goals as well as patient-identified health and wellness goals, and encourage ONC to capture and include both in the common clinical data set.

In developing rules focused on the common clinical data set for purposes of treatment (A1.1),[2] we urge that ONC:

- <u>Use the HHS standards for demographic data collection.</u>
  We encourage ONC to transition from the current (OMB) standards for race and ethnicity data collection to the HHS standards. The HHS standards build upon the Office of Management and Budget (OMB) standards but add essential granularity for Asian and Latino populations (as is currently offered by the American Community Survey (ACS) and Decennial Census). Proper identification of important characteristics of sub-populations is necessary because different ethnic groups often have vastly different health profiles.[3]

- <u>Add ***disability status and functional limitations*** as well as ***sexual orientation/gender identity*** (SO/GI) to the common clinical data set.</u>
  Patients' disability status, functional limitations and SO/GI health information are crucial, clinically-relevant information that needs to be captured and exchanged among multiple health care providers. Including patients' disability status, functional limitations and SO/GI data as elements of a common clinical data set will help to ensure that all patients receive appropriate care specific to their individual needs, and thereby help to reduce health disparities.[4,5] Furthermore, we encourage ONC to capture more granular data

[2] To help ONC, our comments here and below identify particular places in the Roadmap's tables by relevant category and number.

[3] Consumer Partnership for eHealth. (2013, August). *Leveraging Meaningful Use to Reduce Health Disparities: An Action Plan*, from http://www.nationalpartnership.org/research-library/health-care/HIT/leveraging-meaningful-use-to.pdf.

[4] Lagu, T., Hannon, N., Rothberg, M., Well, A., Green, K., Windom, M., Dempsey, K., Pekow, P., Avrunin, J., Chen, A., & Lindenauer P. (2013, March). Access to subspecialty care for patients with mobility impairment: A survey. *Annals of Internal Medicine*, 158(6):441-446.

[5] The Fenway Institute & Center for American Progress. (2013). *Asking patients questions about sexual orientation and gender identity in clinical settings: A study in four health centers.*

about specific disability status and functional limitations, rather than a simple "yes/no" question regarding disability.[6]

Moving forward, ONC should also work with individuals, patients and caregivers as it considers how to expand this core clinical data set, such as including social determinants of health, community resources, etc. (A2.3).[7]

IV. Priority Use Cases

CPeH submits these three use cases to inform ONC's priorities for the development of technical standards, policies and implementation specifications. We recommend these use cases because they encompass multi-faceted consumer priorities and are broadly representative of patients' priority issues, namely online access to health information, the ability to communicate and share information with care team members, and electronic tools to use this information in the pursuit of better care and health.

- Patients have the ability to access their holistic longitudinal health records when and where needed (#18)
- Individuals regularly contribute information to their EHRs for use by members of their care team (#37)
- Individuals integrate data from their health records into mobile apps and tools that enable them to better set and meet their own health goals (#7)

In addition, we respectfully offer a critical use case that is missing from Appendix H – a use case dedicated to leveraging health IT to better identify and reduce health disparities.

- Providers and systems collect electronic health information (such as granular demographic data, patient-generated health data, data about social determinants of health, etc.) and use health information technology (such as stratifying quality measures by disparities variables) to reduce health disparities

V. Governance

The Consumer Partnership comments below on the Roadmap's proposed governance principles and operations.

<u>Policy</u>

We support the policy issues outlined as part of ONC's Governance Principles, particularly access to personal health information, individual choice (with regard to use and sharing of personal health information), transparency and ability to correct health information. We also strongly support development of a policy framework for exchange of patient-generated health data (A2.2) in the next three years, and call attention to our other comments on patient-generated health data (PGHD). (*See section VI below, on C1.3.*)

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[6] The American Community Survey, administered by the US Census Bureau, uses a set of six questions related to disability that has been well-researched and validated. Brault, M., U.S. Census Bureau. (2009, September). *Review of Changes to the Measurement of Disability in the 2008 American Community Survey,* from http://www.census.gov/people/disability/files/2008ACS_disability.pdf.

[7] The Institute of Medicine has already recommended social and behavioral domains and measures for electronic health records in order to capture social determinants of health, illustrating the importance of including behavioral and mental health services and supports. Institute of Medicine. (2014, April). *Capturing Social and Behavioral Domains in Electronic Health Records: Phase 1*, from www.iom.edu/Reports/2014/Capturing-Social-and-Behavioral-Domains-in-Electronic-Health-Records-Phase-1.aspx.

- ***Access to Personal Information***: We strongly support access to personal information being among the first policy priorities to be addressed in governance efforts, and particularly appreciate the emphasis placed on individual preferences regarding release of information.
- ***Individual Choice:*** To advance information exchange across the care continuum, patients and providers must feel comfortable electronically sharing certain types or categories of sensitive health data (i.e., substance abuse information, mental health history, etc.). Continued development of regulatory and technological solutions for ensuring the protection of sensitive health and behavioral health information is critical to patient safety and well-being. We strongly support providing individuals with easily used and accessible electronic processes that reflect the scale, scope and legal sensitivity of personal health information.
- ***Transparency:*** We support the policy provision that data holders should provide to individuals, patients and families easily understandable and accessible information about organizations' data practices, including the providers and entities with which information is being exchanged. Data from the National Partnership's 2014 survey[8,9] underscore the importance of informing and educating patients and families about how their information will be collected, exchanged and used. (*See section VII below.*)
- ***Individual Access and Correction:*** We strongly support the policy focus in 2015-2017 on providing individuals with the ability to correct their personal health information in a timely manner that is appropriate to the sensitivity of the data. Amendments are an important form of patient-generated health data (PGHD). Increased access by individuals to their own health information (as a result of efforts such as Blue Button and Meaningful Use) will surely increase the number of errors identified by patients, thereby underscoring the need for this capability. Providing individuals with an ability to correct information helps to ensure the accuracy and reliability of data, and underscores that patients are important sources of clinical information (D2.2). **However, we encourage ONC to accelerate its timeframe for supporting individuals' ability to request corrections to their electronic health information, as the HIPAA Privacy Rule already grants.** (*See section VI below, on C1.3.*)

Operations

Inclusive Governance: We strongly support requiring consumer/patient involvement in any coordinated governance process tasked with developing common rules of the road regarding trust and interoperability. The Roadmap is missing an explicit Call to Action for individuals, patients, families and consumer advocates to participate in coordinated governance activities throughout the ten-year time frame. (*See section VI below.*)

Patient representatives and family representatives each bring unique perspectives that can help to advance interoperability. Including patients, family members and consumer advocates on governing boards and bodies will ensure that these unique perspectives and use cases are considered in the development of policies and procedures.[10] Bringing such insights to light,

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[8] National Partnership for Women & Families. (2014, December). *Engaging Patients and Families: How Consumers Value and Use Health IT*, from http://www.nationalpartnership.org/research-library/health-care/HIT/engaging-patients-and-families.pdf.

[9] Harris Poll conducted the survey for the National Partnership for Women & Families online in April-May 2014. The 2,045 adult respondents had an ongoing relationship with a main doctor and knew whether the doctor was using an EHR or paper-record system. After weighting, the pool represents 68 percent of adults nationwide, or an estimated 160 million Americans.

[10] For example, to be truly inclusive of individuals with disabilities, it is important that relevant governing boards and bodies include both adults with disabilities and parents of children with disabilities, rather than collapse the interests and perspectives of these two groups.

however, requires engaging patient and family representatives in meaningful ways. We define meaningful involvement of consumer/patient representatives as follows:[11]

- Proportionate representation. Proportionate representation requires having more than one patient, family caregiver or consumer representatives on the governing boards and bodies.
- Representatives are meaningfully involved in decision-making. All representatives, including patients, families, consumers and providers, have an equal seat at the table and an opportunity to share their perspectives as decisions are made.
- Consumer representatives are "true" consumers. The primary interest of "true" consumers is the needs and interests of consumers, patients and families. Consumers have no direct financial stake in the health care system.
- Representatives include both consumer advocates and patient representatives. While consumer advocates include, for example, non-profit organizations or faith-based groups, patient representatives, on the other hand, are patients or family caregivers. Both bring unique and valuable perspectives to the table.

Historically, many health care entities have struggled to engage consumer/patient representatives meaningfully. Consequently, successful partnerships with consumer representatives on governing boards and bodies will likely require ongoing support and oversight from ONC. In defining a nationwide governance framework, we urge ONC to work with consumer advocacy organizations, industry leaders and other stakeholders to develop best practices for sustained and meaningful engagement of consumer/patient representatives.

VI. Supportive Business, Clinical, Cultural and Regulatory Environments

The Consumer Partnership comments below on many of the Roadmap's provisions supporting the equal participation of individuals, families and caregivers in business, clinical, cultural and regulatory environments.

A supportive business and regulatory environment that encourages interoperability

Under the current fragmented fee-for-service payment model, there are few incentives to share data. Interoperability is a key component of broader efforts to move toward a value-based health care system, and health information exchange is fundamental to achieving the improved quality, care coordination, patient-centeredness and cost reduction goals of many new models of care delivery and payment. Successful reform, however, will require buy-in from a broad range of health care stakeholders that pay for care, including consumers. We strongly support using a variety of incentives, payment adjustments and requirements to support health information exchange and improve interoperability.

Going forward, all alternative payment models should be required to demonstrate how they are using (or planning to use) interoperable technology to advance health information exchange in care coordination and quality improvement (B1). Evaluation of programs should also include providers' performance on quality measures that are indicative of whether or not care was coordinated and information was exchanged electronically.

[11] Carman, K., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Affairs*, 32(2): 223-23.

We particularly support the proposal that ONC will reinforce through its funding programs the ability of individuals *and* providers across the care continuum to send, receive, find and use a common clinical data set through its funding programs (B1.4). To this end, we encourage ONC to strengthen and expand current requirements for individuals to be able to view, download and/or transmit their own health information, and electronically exchange secure messages with their providers, building upon Stage 2 of the EHR Meaningful Use Incentive Program.

We also support the intent to move toward aligned e-clinical quality measures (B1.5), but note that there are significant measurement gaps in areas that encourage health information exchange. There is an urgent need to fund the development of new e-measures that tell us more about the quality of care provided and that better reflect larger health goals for our delivery system, such as care coordination, health outcomes and shared decision making.

Individuals are empowered, active partners in their health and health care

We applaud ONC for emphasizing the idea of *partnerships* between individuals and health care providers in the pursuit of better health. As the Roadmap notes, too often in health care, patients are passive recipients of health care services rather than active and equal partners with care providers in the pursuit of better health and care. Moving toward these kinds of partnerships will require significant cultural changes among both patients and providers. CPeH is eager to work with providers, government, payers and health IT developers in supporting and empowering individuals in this manner.

In the execution of the Roadmap's goals, we encourage providers to view patient engagement not as a static concept, but rather a dynamic process. Not all individuals will be engaged in the same way, and the same individual might need different engagement strategies at different points in her life. In support of this idea, the National Partnership for Women & Families identified seven strategies to engage patients and families across different stages of their health in its 2014 survey.[12] It finds, for instance, that some individuals may be first attracted to online access by convenience features, such as appointment scheduling or bill payment, and using these features may make them more comfortable with utilizing more robust features in the future. As we work collectively to strengthen partnerships between patients and providers, we offer this consideration as a key to success.

To achieve true transformation, collaboration and partnership with patients and families must take place at all levels of care (i.e., point of care, practice redesign and governance/oversight). Although section C outlines several important actions that can be taken to engage and empower consumers, **we encourage ONC to add a Call to Action across the ten-year trajectory explicitly encouraging the robust and meaningful participation of individuals, patients, caregivers and consumer advocates in the evolution of nationwide coordinated governance.** We point out that a specific Call to Action for providers to participate in governance was included in D1.1, and we urge ONC to include a similar recognition for individuals.

C1. Culture change for individuals, including demanding and using their health information

We wholeheartedly agree that providing electronic access to health information is fundamental to individuals' ability to cultivate meaningful, active partnerships with their providers (C1.1, C1.2). However, individuals and their caregivers do not need to *demand* access to their health information; they have this right under the HIPAA Privacy Rule. Additionally, the

[12] National Partnership for Women & Families, *Engaging Patients and Families*, p. 28.

current language regarding individual demand – while undoubtedly enthusiastic and proactive – could inadvertently impair the partnerships we are trying to build between patients and health care providers. We encourage ONC to focus on ensuring that a majority of individuals and their caregivers *actively use* electronic health information in a format they can use in 2015-2017, and increasing further the proportion of individuals and caregivers who *actively use* electronic access to their health information in 2018-2020.

As we work to expand consumers' access to electronic health information, we appreciate ONC's recognition that this information also needs to be useful and usable. We encourage ONC to consider what features consumers want and need, in order to maximize the value and utility of electronic health information.[13,14] For example, the National Partnership's survey finds that patients want more robust functionality and features of online access than are available today, including the ability to set and track goals for their health. Additionally, patient-specific educational materials should be added to the list of information available for consumers to view online, download and transmit under Stage 2 of the Meaningful Use Incentive Program.

We respectfully remind ONC that in order to provide electronic information to *all* individuals in a format they can use, progress must be made in making health information available in non-English languages for nearly 60 million Americans who speak languages other than English at home. For example, a Spanish speaker who receives her hospital discharge instructions electronically, but in English only, will not be able to *use* that information – a crucial component of true interoperability. Because more than 37 million Americans speak Spanish at home, at a minimum we should be working now towards providing 100 percent of health information, including patient-specific educational resources, in Spanish.[15] Interoperability for all also requires that we work towards providing access and information in other languages as well, in accordance with the person's language preferences captured in the "demographics" criterion of certified EHR technology.

We are delighted to see language throughout the Roadmap that recognizes patient-generated health data as valuable clinical information, and appreciate the prominent discussion and proposed actions towards incorporating PGHD into EHRs. We also appreciate the complexities involved in establishing processes and procedures for receiving, reviewing, recording, and responding to PGHD. However, we note that the current six-year timeframe (2018-2020) to support the contribution and use of patient-generated health data is too long to wait (C1.3). Individuals are taking advantage of electronic access to their health records today. As patients and families get easier access to their medical records and health data, possibly for the first time, it is inevitable that they will have feedback – corrections, additions and observations to share.

Therefore, we must prioritize the electronic receipt and incorporation of patient-submitted corrections to their record in the next three years (2015-2017). This narrow but critical type of PGHD has important implications for data quality and subsequent use of that data in care delivery. Providing patients an easy way to submit corrections or amendments to their data electronically will be essential to improving accuracy of electronic health information and keeping patients both engaged in and trusting of EHRs and other health IT. **We urge ONC to accelerate its vision for equipping individuals with the ability to request corrections to their electronic health information**. Individuals should be able to contribute corrections within the

[13] Ibid, p. 28.
[14] Ibid, pp. 29-32, 36-37.

next three years, and other types of clinically relevant patient-generated data in the 2018-2020 timeframe.

Finally, we applaud ONC on its Call to Action in 2018-2020 that individuals and their extended care teams (including family and caregivers) should utilize care planning to capture individual goals and preferences as part of longitudinal health information used across care settings (C1.4). This goal aligns with consumers' vision for next generation care planning in an electronic environment, which connects individuals, their family and other personal caregivers, and health care and social service providers, and provides actionable information to identify and achieve an individual's health and wellness goals.[16]

C2. Providers and technology vendors supporting individual empowerment

We believe that these recommendations are critical to creating the supportive clinical culture necessary to allow individuals to access their information and make informed decisions about their care. ONC's proposed goals strive to create a clinical environment that respects individual choice, which is crucial in the pursuit of a person-centered learning health system. Specifically, we commend the goal regarding the incorporation of PGHD that allows the capture of patients' care preferences, particularly advance directives (C2.6). The incorporation of these types of data provides the process to infuse patients' values, goals and preferences into medical care and wellness needs, as well as an opportunity for shared decision-making.

We encourage developers to consider individuals as key users of health information technologies in any user-centered design efforts, including but not limited to functionalities that provide the abilities to send and receive their health information, contribute PGHD and aggregate health information (C2.3, C2.6, C2.7). We applaud ONC's incorporation of human-centered design in the Core Technical Standards building block (J3.4) and suggest that ONC apply this concept throughout the Roadmap as it discusses the need for usable and useful technology.

C3. Privacy and security

We discuss privacy and security in greater detail below. (*See section VII below.*) We note here our strong support for the Call to Action that providers provide individuals with secure and easy access to their own behavioral health information (C3.2). Secondly, the National Partnership's recent survey of how consumers value and use health IT already reveals that many patients need and want better explanations of how their health information is collected and used, and protected. We do not need further assessment of *whether* there is a need (C3.1); we need actions to meet that need.

C4. Education and health literacy for individuals

We appreciate the Call to Action specifying the involvement of consumer advocacy organizations in the development and dissemination of resources to increase individuals' digital health literacy (C4.1). We agree that consumer advocacy groups have unique knowledge of consumer/patient issues and priorities, as well as established relationships, and are well positioned to *inform and guide* the development and dissemination of educational materials and other resources. However, many consumer advocacy organizations lack the resources necessary to undertake such efforts on their own.

[16] Consumer Partnership for eHealth. (2013, November). *Care Plans 2.0: Consumer Principles for Health and Care Planning in an Electronic Environment*, from http://www.nationalpartnership.org/research-library/health-care/HIT/consumer-principles-for-1.pdf.

We commend ONC's emphasis on digital health literacy as a critical component of broader health literacy. Some individuals may require increased technological support and assistance, which in turn may affect consumers' likelihood and ability to electronically access and use their health information. Addressing literacy in English can also help individuals with limited English proficiency until the information is made available in the preferred language, by using low-literacy materials to aid understanding and subsequent translation into the preferred language. These activities to enhance individuals' understanding and engagement should take place *now,* as well as in the next six to ten years, if we are to move towards a learning health system by 2024.

Efforts to improve digital health literacy are important, and we underscore the need to create digital tools that address the varying states of digital health literacy *now*. Consumer-facing technologies must provide information in terms that individuals can understand in order to support consumer participation in shared decision-making. We believe that increasing the overall usability of health IT tools will simultaneously enhance digital literacy and enhance individuals' meaningful participation in their health and care. We encourage technology vendors to partner with individuals, patients and families to develop patient portals, care planning platforms and other consumer-facing health IT tools. (*See section VI above, on C2.*)

Care Providers Partner with Individuals to Deliver High-Value Care

D1. Providers embrace a culture of interoperability

We strongly support the Call to Action that providers recognize and incorporate into their decision-making the valuable clinical information generated by patients and caregivers (D2.2). This widespread and inclusive view of patients as important sources of information helps to empower individuals to be active partners in their health and health care, and is critical to realizing meaningful partnerships between providers and patients.

D3. Accurate Measurement

The development of standard metrics for interoperability should also capture the patient or family/designated caregiver's assessment of electronic information sharing (D3.3). For example, if referred, was the patient's electronic information received at the secondary provider's office by the time of the patient's visit? Did secure messages receive timely responses?

VII. Privacy and Security Protections of Health Information

We appreciate ONC's careful attention in the Roadmap to the privacy and security of individuals' health information. Trust, privacy and security are interrelated and are critical to the practice of interoperability. In fact, the National Partnership's survey identifies a mutual reinforcing relationship between use of online access – an essential form of information sharing – and consumers' trust in their providers. It found that **online access enhances that trust, and more frequent online access enhances it significantly more**: Patients who have online access and use it more frequently (3 or more times per year) have significantly greater trust that their providers will protect their privacy and other patient rights (84 percent trusting "completely" or "a lot," compared with 69 percent).[17]

[17] National Partnership for Women & Families, *Engaging Patients and Families,* pp. 39-40.

We also applaud the Roadmap's attention to encryption at rest and in transit (E2). *If used*, encryption provides security and privacy that paper records simply cannot – and individuals can appreciate that protection.

Verifiable identity and authentication of all participants

In its discussion of identity proofing and authentication, the Roadmap rightly includes settings relevant to individuals, patients and family caregivers, such as *patient portals* and *mobile access*, alongside settings traditionally considered for providers. We appreciate ONC's equal consideration of requirements and platforms that apply to patients' and individuals' access. We note that such requirements must work across the diversity of America's patients and individuals (e.g. different languages, HIT literacy levels, disabilities, cultures) and the different settings (e.g. private and public settings, urban and rural locations) and platforms (e.g. desktop, smartphone) that different individuals might use. These very same issues have arisen with the marketplace exchanges to enroll individuals for health insurance, and ONC may find excellent thinking and best practices in the work there to design identity proofing and authentication for the range of people across the country.

Consistent representation of permissions to collect, share and use identifiable health information

We appreciate ONC's recognition that attention is required to helping individuals understand how their information is being exchanged for treatment, payment and operations. The National Partnership's survey found that patients want better explanation of privacy and security protections, and particularly how their medical and health information is collected and used. Eighty-eight percent of EHR patients and 82 percent of paper-record patients state that it is important to them to know how their information is collected and used, but less than 60 percent report that their doctors and staff do a good job of explaining this.[18] This highlights a continuing education gap that the Interoperability Roadmap would do well to address.

VIII. Certification and Testing to Support Adoption and Optimization of Health IT Products and Services.

We applaud ONC's plan to consider expanding the certification program to support health IT across a broader set of care settings, such as long-term and post-acute care, home and community-based services, and behavioral health settings. Such integration and interoperability are important as well in developing the broader learning health system.

We applaud as well that ONC intends to examine criteria related to accessibility and usability of health IT. Accessibility and usability of health IT, including online access and patient portals, are equally important issues for individuals and families, just as the usability of EHRs has been an important issue for providers and hospitals. Capturing patients' and individuals' views, through listening sessions, for instance, would be welcome. Additionally, we encourage ONC to prioritize criteria that enable the kind of granular disability, functional impairment and accommodation questions that are necessary to ensure full accessibility. This is especially important as the incorporation of older established IT systems can lead to development decisions that limit the capacity of the newer systems that must interact with less accessible databases and information gathering procedures (rather than increase accessibility in the older systems).

[18] Ibid, p. 40.

IX. Core Technical Standards

The Consumer Partnership comments below on new standards and priorities such as usability, accurate individual data matching and essential resources to locate and incorporate.

Consistent data format and semantics

Develop and pilot new standards for priorities

In its discussion of developing new standards, we appreciate ONC's Call to Action for standards developing organizations to advance consumer-friendly terminologies (J3.3). We seek clarification on this term, and also hope that the reference to consumer will extend both to the providers who utilize these technologies and to patients as frequent end users. Consultation of both providers and patients is critical in determining the consumer-friendliness of these technologies.

We applaud and strongly support the Call to Action for developers to advance human-centered design, as this concept captures usability for all users (including consumers) and goes beyond the traditional thinking often limited to providers (J3.4). We are delighted to see proposed efforts to make this information truly usable and useful to consumers through the provision of electronic health information to consumers in languages other than English and through accommodations for varying levels of literacy. Efforts to make consumer-facing technologies more accessible and usable should also consider the specific technical requirements that would make health IT accessible to users with visual, mobility, print and other disabilities.

Finally, we commend the proposal urging industry guidance on the exchange of unstructured data such as physician notes (J3.7) and hope that this envisioned exchange reaches individuals as well as providers. This type of information is essential to helping individuals better manage their health and care and partner more robustly with providers.

Accurate individual data matching

We applaud ONC's commitment to addressing critical data quality issues, such as data provenance and patient matching, in the early years. Regarding individual data matching, ONC, providers and developers should take into account the diverse characteristics and attitudes among patient populations when designing patient matching processes and choosing the minimum recommended data elements for patient matching. For example, address might work well for many, but does not work well for homeless individuals. No single attribute will work equally well for all patient populations and regions, and the task should be to identify the combination of minimum attributes that collectively works best across the diversity of patient populations. Any development of standards for patient data attributes should acknowledge the wide ethnic and cultural differences among patients, to the extent possible.

Regarding data quality, we again encourage ONC to consider patients and families as part of the solution to resolving data quality and integrity issues. Patients can improve data quality by reviewing their medical records, providing amendments and corrections and supplying missing data – which can affect patient matching. This role that patients and families can play in improving data quality underscores the need to develop processes for patients to submit corrections and amendments to their record. This role also underscores the importance of removing unnecessary barriers to access. For example, for the 60 million people who use a

language other than English at home, providing electronic access in languages other than English could do much to reduce errors in their data attributes and in matching.

Reliable resource location

We encourage ONC to consider community resources and supports when developing resource location services and directories as part of an expanded set of resources (N1.2).

X. Measurement

We applaud ONC for its commitment to ongoing evaluation and measurement to support continuous quality improvement in achieving interoperability, and appreciate ONC's recognition that this measurement process must involve a feedback loop. The framework employed to create measures across the 3-, 6- and 10-year timespan is a logical, incremental framework. We strongly agree with ONC's attention in Figure 11 (measures for 2015-2017) to domains and measures that directly impact and involve individuals. **Longer-term measures (Figure 12) should likewise explicitly include and apply to individuals and family caregivers.**

Thank you once again for this opportunity to provide input into ONC's vision and plan to achieve an interoperable health IT infrastructure within ten years. If you have any thoughts or questions about these comments, please contact Mark Savage at (202) 986-2600 or MSavage@nationalpartnership.org. Consumers look forward to partnering with government, industry and other stakeholders to improve interoperability and move to a learning health system from which individuals, patients and families have much to benefit.

Sincerely,

Alliance for a Just Society
American Association on Health & Disability
American Cancer Society Cancer Action Network
Association of Asian Pacific Community Health Organizations
Boston Public Health Commission
California Pan-Ethnic Health Network
Caring From A Distance
Connecticut Health Policy Project
Consumers Union
Disability Rights Education and Defense Fund
Family Caregiver Advocacy
Genetic Alliance
Healthwise
Maryland Women's Coalition for Health Care Reform
Morehouse School of Medicine
National Consumers League
National Health Law Program
National Partnership for Women & Families
Morehouse School of Medicine
The Children's Partnership
Universal Health Care Action Network Ohio

Mary Anne Sterling, Family Caregiver Advocate