Consumer Work Group
Federal Health IT Strategic Plan Comments

We are pleased that the HITPC asked the Consumer Work Group (CWG) to comment on the Federal Health IT Strategic Plan. This role is essential to elevating consumer voices in shaping the nation's health IT policy in ways that are patient--- and family---centered. We applaud the significant amount of effort and federal agency coordination put forth in developing the plan; it reflects a multi---faceted approach to expanding adoption of health IT; advancing secure and interoperable health information; strengthening health care delivery; advancing the health and well being of individuals and communities; and advancing research, scientific knowledge and innovation.

The charge of the Consumer WG is to provide input and make recommendations on policy issues or opportunities to use health IT to:[1]
1. Engage consumers and families in their own health and health care
2. Enable consumer---provider partnerships supported by health IT
3. Elevate consumer voices to shape health system transformation

These three areas comprise the framework we used to organize our specific comments below. We begin by providing comments on the high level components of the strategic plan first (Overview, Principles, etc.) and then follow with specific comments relevant to the Goals, Objectives and Strategies.

General Comments:
Overview:
- The Work Group recommends that the overview include a definition of health IT, the scope of which should cover consumer facing health IT like mHealth, etc., and not just EHRs. We also encourage you to define other terms throughout the plan, such as mHealth and precision medicine. Clarity in terms will help consumers better understand the Plan. Lastly, the Work Group proposes this edit on page 4: "It strengthens the delivery of health care, *including behavioral health and* long---term services and supports, and allows public health agencies to detect, track, manage, and prevent disease outbreaks. Information also fuels research and innovation, spurring advancements in scientific discovery."

Strategic Goals, Objectives, and Strategies
- The "Collect, Share, Use" framework is focused on data, and the Work Group is concerned that consumers will not relate to this framework. The ecosystem of health IT should have people at the center, and should reinforce the collaborative relationships needed to improve health and care. Collect---share---use also might be misinterpreted as reinforcing provider/system ownership and control of data, a position that is contrary to other themes in the Plan.

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[1] Note that we use the words consumer, patient, individual, person throughout our comments in different contexts. There is no widely---agreed upon approach to terminology today, and we agree with the National Quality Forum that "one single term cannot apply to all individuals in all situations; in actuality, an individual with many needs may self---identify as a person, client, or patient at a single point in time." Generally speaking, we are referring in all cases to people who receive and manage their health care.

- The Work Group suggests shifting the focus more to individuals vs. data, including consideration of existing health policy rubrics that center on improving health and care, such as the Triple Aim.

Strategic Plan Development & Update:

- We understand that the Plan will be further updated with measures that indicate federal government progress toward the Outcomes. We fully support that effort and hope reporting on progress will be transparent to the public in the future.

Federal Health IT Principles: The Work Group supports the Principles set forth, but the following additions would strengthen the Principles and elevate issues important to consumers:

- Leveraging health IT to empower consumers in their own health and care, and empower family caregivers with information and tools they need to support their loved ones in health care transition, medication management, treatment and recovery.
- Equity– for consumers and providers. How health IT can increase health equity and reduce disparities, and how we must ensure equitable adoption among provider populations that serve our most vulnerable individuals, including individuals of limited financial means and those with limited English proficiency.
- Using health IT to improve patient and family experience of care and ensure care is concordant with the personal goals of the patient.

Comments on Specific Goals, Objectives and Strategies:

Overall, we are pleased to see an objective focused on consumers (4A). However, it is also essential that consumers (as partners in care and system design) are visibly reflected in each major area, such as governance mechanisms for information sharing, shaping public health initiatives, advancing precision---medicine, determining research priorities, etc. Objective 4A is important, and we offer comments to strengthen it, but we encourage ONC to ensure that strategies pertaining to consumers are visibly part of each objective.

In addition, the Work Group was pleased to see Objectives and Strategies relating to care planning, shared decision making, patient---generated health data and more, but observes that they are spread throughout different Goals, potentially diffusing their focus and impact. Yet these are priority areas for consumers. Further, the Work Group sees a gap between Goal 3 (Strengthening Healthcare Delivery), which is focused heavily on providers, and Goal 4 (Advance the Health and Well Being of Individuals and Communities), which includes an objective focused on consumers. There is an important bridge between these two concepts that can better align federal activities to leverage health IT in ways that achieve health outcomes that matter to individuals and families: that bridge is a partnership to advance person---centered health and care goals.

Health IT should play a crucial role in supporting care delivery systems and individuals coming together (e.g. partnership) around shared goals for their care, and aligning patient engagement efforts as well as quality measurement, reporting and payment efforts around those objectives. The end result will be a health care system that consistently, continuously and collaboratively works with individuals to document, measure, refine and communicate the objectives that are both meaningful to the patient and achievable by the delivery system.

Thus, the Work Group suggests new Goal between Goal 3 and 4: **Building a culture of individual, provider and community partnership to achieve shared health and health care goals**. The focus of this goal would be leveraging health IT such that individuals, providers, community---based organizations and other patient supports can partner together to identify, align to and achieve patient goals.

This new Goal in the Strategic Plan could include several existing/revised Outcomes and Strategies under its umbrella: care planning, shared decision making, patient---generated health data, health literacy and communication, access to and use of clinical trial data, and more. In addition, this new Goal could be further buttressed by additional Strategies that advance the role of health IT in areas such as advance directives and social determinants of health (which we comment on further below). The Work Group also suggests consideration of strategies around quality measurement and payment incentives – specifically, evolving the ability of health IT to efficiently measure quality in the areas of progress toward goals, including process and outcomes measures that are shared between the individual and their care providers; as well as corresponding alignment of incentives for care providers/teams and individuals to document and meet shared goals for health and care.

Our specific comments on the proposed Objectives and Strategies are as follows:

Engage Individuals and Families in their own health & health care
Ability for consumers to aggregate data from multiple sources (e.g. different portals, wearables, eVisits, etc.): This concept is not clearly reflected in the plan for consumers. We are concerned that consumers will now have many portals that don't connect as a result of federal policy. Too many portals with too many passwords to memorize may lead to a lack of consumer engagement around these tools. In addition, consumers are generating health care data outside their care team that their providers need to deliver safe, high quality care: consumer---oriented services such as multiple apps, urgent care clinics, retail clinics potentially could increase fragmentation. Patients and family caregivers need the ability to pull data together in one place and share relevant data seamlessly and efficiently with the care team. ONC should consider this under Objective 4A and under 2A (page 14) and reference it under Objective 3A --- in other words, expanded use of health IT should not just focus on providers but include consumers as well. It should in fact support partnership between consumers and providers, since consumers are the common denominator across all health care encounters and thus have the most knowledge of their data sources. Further, Objective 2A Strategy 5 should include consumers as well – not just health providers and payers. However, consumer---driven aggregation needs serious consideration in terms of where this aggregation occurs, e.g., in provider---controlled or consumer---controlled spaces. Such aggregation also raises the privacy and security issues and, as discussed elsewhere, if the aggregation takes place in private entity/consumer space, it entails a different and less robust regulatory framework. Please see our comments in the privacy section.
Portal usability and design for consumers (to advance a wide array of functions consumers care about): Making consumer---facing health IT such as portals more user---friendly for consumers and more functional for both consumers and providers is part of creating person---centered care and belongs in Goal 4 as well as Goal 1, Objective A (increasing adoption) and Goal 3, Objective (improving access and experience). ONC should also include an explicit emphasis o consumer---facing products under Objective 1B, Strategy 3 which focuses o user centered design, health literacy and more. ONC should consider ways to incentivize the development of needed features for consumers such as use of plain language and languages other than English, accessibility for people with disabilities, health IT literacy, etc. It may be worth exploring how to incentivize user---centered design, participatory research and potentially certification for consumer---facing health IT so that consumers, patients, and caregivers are involved at every stage, from concept to launch and evaluation. However, ONC should carefully explore the intended and unintended consequences of such certification. In addition, ONC should monitor portal implementation from consumer perspectives, particularly as we hear examples of providers charging patients extra fees for the use of portal features that are more advanced.

Access to health information thru mobile devices (mHealth): We assume increasing individuals' ability to access health information (page 22) would include clear emphasis on mobile technologies and smart phones but ONC should clarify this under Objective 4A. It is not specifically mentioned in 4A but it is in Objective 1A, Strategy (adoption) and in Objective 3A, Strategy on page 1 (incorporation into federal programs). ONC should focus in not only ways it can increase individuals' access to health information via mobile devices, but also increasing their ability to contribute, share and manage their health information on mobile platforms. We support consideration of appropriate payment for mHealth and telehealth. Overall, the area of mHealth should be more clearly defined. We are glad to see the emphasis on mHealth security in Objective 5B Strategy 2. (More comments in the Privacy Section) .

Addressing digital divide at consumer level: We are pleased to see an emphasis on improving broadband. We also encourage ONC to track rates of Smartphone adoption/use and consider policies that enable vulnerable populations to effectively use their health information as needed on this platform (e.g., considering cost of data, cell plans, etc. for financially vulnerable individuals). Further, ONC should create outcomes that focus on equity and strategies that help address health disparities. Strategy Plan Location: Goal 1C, strategy 1, and 3. Along with more access to mobile devices and to broadband, the strategic plan should also incorporate incentivizing community health practitioners and local leadership to provide access, for example, through public space computers in FQHCs, libraries etc.

Health literacy, clear communications: We strongly support Objective 1B, Strategy 3 as well as Objective 3A Strategy on pg. 18. However, we also strongly believe the federal government should have 3 and 6 year outcomes related to improving health literacy. Health literacy should also be included in Objective 3A. We also believe that health IT literacy for consumers is an important part of HIT usability and safety (Objective 1B) and a new strategy could be part of Objective 4A: "Education for consumers on Health IT concepts and tools." As noted elsewhere, this would likely be done by leveraging ONC and CMS relationships with providers.

Enable partnerships supported by health IT

Patient Generated Health Data (PGHD): We strongly support Strategy 5 on pg. 18, as well as Objective 4A , Strategy on page 22, although it is unclear how these strategies --- both of which relate to PGHD --- differ and why they are found in separate places. But a single strategy could be considered in light of the new goal the Work Group proposed above. Also, we are pleased to see an Outcome related to PHGD, but we suggest that the first 6---year Outcome in this Objective ("Expand the ability…") should be a 3---year Outcome,. ONC has done previous work on this issue, and PGHD was proposed by the HITPC for MU3, indicating that this timeline can be accelerated. ONC and CMS should use their outreach and education efforts to promote the patient experience and incorporate advanced care planning as one form of PGHD. Other avenues for advancing PGHD could include:

2B, 6---year outcome: Improving health IT's ability to manage unstructured data has positive implications for facilitating collection and use of PGHD
3A, Strategy 5: Collect and integrate PGHD as routine part of care supports and delivery.
4A, Strategy 1: Corrections/amendments important but so are other kinds of PGHD (i.e., patient goals, caregiver status, etc.)
4A, Strategy 3: Incorporating PGHD into medical records for use in treatment, other decisions is critical.

It may be necessary to define data standards for the transmission of PGHD from mobile devices to electronic health records.

Person---centered (care) planning: Objective 4A should include a specific strategy to advance person---centered planning – e.g., person centered services and supports plan, oriented around and driven by patient goals, which integrates general health care, behavioral health, and community---based organizations, including organizations that serve persons with disabilities. It is a process highly desired by consumers, family caregivers and providers. It is also consistent the statutorily required and evolving CMS CARE --- continuity assessment record and evaluation. It is also consistent with recent CMS person---centered planning in home and community---based waiver programs and Medicaid managed care programs. This objective should be clarified and placed under the consumer---oriented Objective 4A to reflect the fact that it should be person---centered process, not a provider---centered one. Re---

thinking the future of care plans should be driven by what patients, families, and providers need. Today's EHRs do not effectively have the functionality both providers and consumers want in this area. It is an essential role for government and, under Objective 2B; the certification program should specifically accelerate creation of this functionality. It will be important however to outline the planning process and the role technology can plan. Once identified, federal payment policies by CMS, HRSA and others should incentivize the use of this process. Shared care planning must also include social determinants of health, advance directives, family caregiver information, community---based resources and social services (including behavioral health), linkages to shared decision making tools as appropriate, patient---generated health data and more. These care plans must also be able to be shared across appropriate providers and individuals treating the patient to foster maximum alignment.

Ability to identify and support family caregivers Under Objective 4A – page 22, Strategy 1 should (at a minimum) include family caregivers. In addition, under Objective 2B, the certification program should specifically accelerate development of functionalities that both identify (name, role and contact information) and support family caregivers; these functions are not well addressed by the market today.

Increase the value for consumers and patients by addressing the "hassle factor" in health care (for patients and family caregivers) in ways that create efficiencies for clinicians too: Health IT functions that improve the accessibility of health care are a major strategy for engaging consumers in health IT use and improving patient experience. Goals 3 and 4 should consider additional strategies that advance the use of functions (many of which have been developed in the market but not universally deployed) through education and technical assistance. Features such as scheduling, bill paying, paperwork/forms, etc. are key to increasing value for consumers as well as use of electronic health information (Strategy 1). •3B, 3---year Outcome: Identify & increase administrative efficiencies that reduce cost and improve provider and patient experiences.

Capacity for shared decision---making: Strategic Plan location: Objective 4A (page 22) --- We strongly support advancing shared decision making for consumers and providers. First, we believe it should be a 3 year outcome, instead of a 6 year outcome. ONC should assess progress in the field and identify ways to accelerate its presence in the market, through certification, payment policy, etc.

Connecting clinicians and patients and families to community resources: Strategy under Objective 3C (p. 20) – ONC should clarify. Does this include helping providers and others to connect patients and families to community resources and social services? We believe it should be clearly reflected in the strategies --- and those strategies should also include helping patients and families connect to these resources o their own via technology. Also, community resources should be part of the person---centered planning process we are recommending become a new strategy under Obj. 4A, above. Finally, the 6 year outcome to "identify" innovative uses of health IT to connect to community resources should be more robust. We believe ONC and other federal partners can identify innovative uses in a far shorter timeline, such that the six year outcome could be focus on actually using health IT to connect to community resources and social services.

In addition, with respect to Goal 1, we recommend that the Plan more explicitly state the goal of full integration of general health care---behavioral health---and community---based organizations (CBOs), including CBOs that serve persons with disabilities.

Privacy: We are pleased to se several strategies related to privacy and security throughout the Plan, including in Objective 2C. Given the increasing use of patient portals, apps, and new technologies and devices that are not covered by HIPAA, ONC and OCR should prioritize addressing policy gaps that exist. It is important for the federal government to identify and advance policy options for those technologies and situations where current privacy and security policies leave consumers/patients/caregivers unprotected, including mHealth applications and more.

Social Determinants of Health There should be a broader focus on this in policy in general, given the recent IOM report and its presentation to the HITPC. In addition, under Objective 2B, the certification program should foster and accelerate the development of relevant functions. ONC should have a specific strategy and corresponding outcome that advances the nation's ability to use Health IT to address the social determinants of health.

ACCESS: First, we are pleased to see federal priorities for advancing telemedicine. However, we do not specifically see eVisits and other forms of access (such as remote monitoring) called out. Care is increasingly moving outside physical institutions. Under Objective 2B, these functions should be part of certification in order to make more EHRs connect with or have these functions. eVisits also will need consideration of other federal policies to support them (payment, etc.) Second, access requires usable health information, and health information is only useful if the user can understand the information. For consumers, this means electronic health information, such as on portal, in an after visit summary, etc., must be available in languages other than English. Facilitating language access is core function where standards and certification criteria could advance the market.

How consumers can drive interoperability Objective 2A Strategy 5 should include consumers – not just health providers and payers. The Strategies under this Objective seem overall to be weak o consumer interests and patient---centricity. While the narrative introduction references consumers, overall this objective appears to focus mostly on how to advance institutional and provider interests rather than patient interests. These interests are not mutually exclusive but the strategy should at least have ONC outlining specific ways that consumers can advance interoperability and data sharing, and cataloguing barriers that may stand in the way. For example, Interoperability combined with PGHD and data aggregation will be crucial to ensuring the health record and data is up to date and accurate for an individual. Portal fatigue will detract from consumers' ability to drive interoperability. Language access and health literacy are also key factors. Further, ONC should get consumer input on what "basic set of essential health information" as well as the "expanded set" referenced in the Outcomes for this Objective.

Elevate consumer voices to shape health system transformation

Implementation support provided includes how to partner with consumers, especially in key areas like PGHD design and implementation: Under Objective 3B, Strategy support for implementation and usability should include helping providers learn how and when to partner with patients and families in implementation --- e.g., working together to design and use a portal, determining how computers are used in exam rooms, selecting and implementing PGHD priorities, etc. This partnership and collaboration is essential to shifting the culture of health care to be patient--- and family---centered and ensuring federal health IT investments are benefitting consumers. This should be a core strategy that the Federal government advances, and Federal incentive programs such as ACOs and PCMH should have partnering with patients in these ways as requirements. Another way to elevate consumer voices in health system transformation is to explore health IT's role in enabling more effective, efficient and real---time collection and use of patient experience data. Patient experience with care, with health IT and with other aspects of a provider's operation is an essential measure of improvement, yet data collection and use for quality improvement remains challenging for providers.

Consumer role in governance of HIE and interoperability initiatives: It is essential for government to accelerate and advance governance mechanisms. The governance mechanism must include robust representation from consumers, from its inception, throughout the process, including developing the rules of engagement. (Objective 2A.)

Training and Education A) For consumers, in terms of how to access and use electronic health information, its value and benefits, as well as privacy issues and B) training and workforce development for providers --- specifically in how to leverage HIT to partner with patients in their care, as well as how to partner with patients to develop and implement new features of technology (such as PGHD). It may be difficult and resource intensive for ONC to directly educate consumers, but ONC and CMS should leverage their reach with providers and facilities to help them educate their own patients and families, as well as to make the case for partnering with patients making them more successful in the long run.

Participating in Research: Under Objective 5A and 5B --- research and innovation are important areas for consumers. They can also be areas of great risk to whether or not consumers trust the system. To address this, the federal government must identify ways to ensure that consumers participate in shaping and governing these initiatives. We also recommend clarifying the definition of "precision medicine."

Again, we appreciate the amount of staff work and coordination required to craft a comprehensive plan, and we thank you for the opportunity to comment. We stand ready to assist you further as needed.

Sincerely,
HIT Policy Committee Consumer Work Group