

# Health IT Policy Committee

A Public Advisory Body on Health Information Technology to the National Coordinator for Health IT



## Consumer Workgroup

### Interoperability Roadmap Comments

Christine Bechtel, chair

April 7, 2015

# Consumer Workgroup Members



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- **Christine Bechtel**, Bechtel Health Advisory Group (Chair)
- **Dana Alexander**, Caradigm
- **Leslie Kelly Hall**, Healthwise
- **Ivor Horn**, Seattle Children's
- **Erin Mackay**, National Partnership for Women & Families
- **Philip Marshall**, Conversa Health
- **Amy Berman/Wally Patarawan**, The John A. Hartford Foundation
- **Will Rice**, Walgreens/Take Care Health Systems
- **Clarke Ross**, Consortium for Citizens with Disabilities; American Association on Health and Disability
- **Luis Belen**, National Health IT Collaborative for the Underserved

- **Kim Schofield**, Lupus Foundation of America (GA Chapter) Work@Health Program for CDC
- **MaryAnne Sterling**, Patient & Caregiver Advocate
- **Nicholas Terry**, Indiana University, Robert H. McKinney School of Law

## Ex Officio Members

- **Cynthia Baur**, HHS, CDC
- **Teresa Zayas Caban**, HHS, AHRQ
- **Danielle Tarino**, HHS, SAMHSA
- **Theresa Hancock**, Veterans Affairs
- **Bradford Hesse**, HHS, NIH
- **Wendy J. Nilsen**, HHS, NIH

## ONC Staff

- **Chitra Mohla**, Office of Policy (Lead WG Staff)



1. Workgroup Charge and Context
2. Overarching Comments
3. Section C Comments
4. Section D Comments



# WORKGROUP CHARGE AND CONTEXT



Provide input and make recommendations on policy issues or opportunities to use health IT to:

- Engage consumers and families in their own health and health care
- Enable consumer-provider partnerships supported by health IT
- Elevate consumer voices to shape health system transformation



# Overarching Comments

# Overarching Comments (2 of 3)



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- Partnership between clinicians, patients and family caregivers should be an essential building block in the Learning Health System (LHS); Building block B already states “a supportive business and regulatory environment that encourages interoperability.”

## Rules of engagement and governance

### A. Share governance of policy and standards that enable interoperability

## Supportive business, clinical, cultural and regulatory environment

- B. A supportive business and regulatory environment that encourages interoperability
- C. Individuals are empowered to be active managers of their health
- D. Care providers partner with individuals to deliver high value care

## Privacy and security protections for health information

## Certification to support adoption and optimization of health IT products and services

### I. Stakeholder assurance that health IT is interoperable

## Core technical standards and functions

- J. Consistent data formats and semantics; K. Consistent, secure transport technique(s);
- L. Standard, secure services; M. Accurate identity matching; N. Reliable resource location

# Overarching Comments (3 of 3)



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- Consider merging Section C & D to support the partnership and streamlining the overall effort of achieving a LHS
- Rapidly changing role of the Consumer and evolution of technology is not well reflected in the overall plan. EHRs appear to be the central focus
- *Global comment:* Replace “others” with “Authorized family members and other authorized caregivers” throughout the roadmap.
- *Global comment:* Replace “care plan” with “person centered plan” because healthcare is a piece of the plan but includes other areas such as community services and long term care services.
- A realistic vision of what interoperability will/should look like in 2024. If truly patient-centric model, the patient will be the dominant curator of health information.





# Specific Comments on Section C

# Section C: Cultural change for individuals including demanding and using their electronic health information

Category	Comments
C1. Cultural change for individuals including demanding and using their electronic health information	<p data-bbox="241 207 1845 328"><b>1. <u>Call to action:</u> A majority of individuals and their caregivers should demand access to their electronic health information in a format they can use to manage their health or that of others.</b></p> <p data-bbox="241 385 1845 556">Roadmap strongly supports empowering and engaging consumers but the term “demand” is not conducive to fostering a partnership between consumer and provider</p> <ul data-bbox="338 571 1845 735" style="list-style-type: none"><li>• Consumers should not have to demand access to their information – right guaranteed under HIPAA.</li><li>• Suggest replacing <u>demand</u> with <u>will</u></li></ul> <p data-bbox="241 799 1912 921"><b>3. <u>Call to action:</u> Individuals should contribute clinically relevant patient-generated health data and request corrections to their electronic health information to effectively manage their interactions with the care delivery system and to manage their health and wellness where they live, work and play</b></p> <p data-bbox="241 978 1816 1092">Consumers need easy, obvious ways to contribute data, as well as to flag inaccurate data using health IT tools.</p> <ul data-bbox="338 1106 1874 1378" style="list-style-type: none"><li>• Amendments/corrections, etc. should be better developed and deployed in the shorter term</li><li>• Systems should be flexible meeting differences in capacity</li><li>• Important advances needed around language access, including offering health information in the top 5 languages nationally</li></ul>

## Section C: Cultural change for individuals including demanding and using their electronic health information, continued

Category	Comments
C1. Cultural change for individuals including demanding and using their electronic health information	<p data-bbox="266 322 1881 462"><b><i>4. <u>Call to action:</u> 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.</i></b></p> <ul data-bbox="266 519 1881 1325" style="list-style-type: none"><li data-bbox="266 519 1881 748">• Accelerate this call to action to support new models of care that are already underway<ul data-bbox="459 648 1881 748" style="list-style-type: none"><li data-bbox="459 648 1881 748">○ Develop functionality along a broader consensus on the attributes of an ideal planning process</li></ul></li> <li data-bbox="266 819 1881 1325">• Person Centered Planning should include (potential data gaps currently):<ul data-bbox="363 948 1881 1325" style="list-style-type: none"><li data-bbox="363 948 1881 991">• Goals for Care</li><li data-bbox="363 1005 1881 1048">• Direction</li><li data-bbox="363 1062 1881 1105">• Advance directives</li><li data-bbox="363 1119 1881 1162">• Values base direction such as religious preferences</li><li data-bbox="363 1176 1881 1219">• Care giver/support team</li><li data-bbox="363 1233 1881 1276">• HHS/IOM Standards for Race/Ethnicity, Language</li><li data-bbox="363 1290 1881 1325">• Social Determinants of Health</li></ul></li></ul>

# Section C: Cultural change for individuals including demanding and using their electronic health information, continued

Category	Comments
C2. Providers and technology developers supporting individual empowerment	<p data-bbox="314 289 1870 382"><b>1. Call to Action: ONC, government and the industry will identify best practices for the incorporation of patient-generated health data in health care delivery.</b></p> <ul data-bbox="314 444 1870 682" style="list-style-type: none"><li data-bbox="314 444 1870 582">• WG supports PGHD - need to focus on implementing already known best practices “on the ground”, identifying new ones, beyond those that have already been developed through white papers and the FACA work.</li><li data-bbox="314 596 1870 682">• Rapidly growing market for devices and wearables a source of PGHD, standards need to be developed and/or agreed to as well as implemented by 2018.</li></ul> <p data-bbox="314 746 1899 839"><b>5. ONC and government ensure that patients understand their ability to access, send and receive health information.</b></p> <ul data-bbox="314 901 1870 1196" style="list-style-type: none"><li data-bbox="314 901 1870 1053">• This should be more comprehensive and focused on digital health literacy: include patient and family education and engagement around understanding the value, and privacy implications of health IT and the “how to”</li><li data-bbox="314 1068 1870 1196">• Develop tool kits for providers as part of a larger digital literacy initiative, as well as consideration of vulnerable and diverse populations who may require different outreach strategies.</li></ul>

## Section C: Cultural change for individuals including demanding and using their electronic health information, continued

Category	Comments
C2. Providers and technology developers supporting individual empowerment	<p data-bbox="316 248 1856 372"><b>6. <u>Call to action:</u> Providers and technology developers should support the incorporation of patient-generated health data in health care delivery, which may include advance directives, remote monitoring, glucose levels and other data individuals are tracking</b></p> <p data-bbox="316 382 1128 419"><i>2018-2020: Expand interoperable health IT and users</i></p> <ul data-bbox="316 429 1856 619" style="list-style-type: none"><li>• Essential in this time frame that providers can easily receive, upload, understand and act upon patient-sourced data in usable and safe ways</li><li>• Consider a <u>new call to action</u>: 2015-2017 for vendors to collaborate with providers in developing capacity</li></ul> <p data-bbox="316 686 1904 896"><b>7. <u>Call to action:</u> Technology developers should deploy innovative aggregation platforms and tools that allow individuals and caregivers to receive and compile health information from multiple sources in one place, send their data to a destination of their choice and find and use the information they need (as determined by the individual), to support for example, the individual participating in shared decision-making with their care team.</b></p> <ul data-bbox="316 906 1895 1100" style="list-style-type: none"><li>• Implement sooner than 2018-2020 for the uptake of Blue Button and VDT, as required in MU2</li><li>• Aggregation platforms will alleviate portal proliferation and portal fatigue</li><li>• Should include link to patient education materials</li></ul> <p data-bbox="316 1162 1779 1248"><b>8. <u>Call to action:</u> Providers should welcome and use information from other providers to avoid duplication of tests and ensure coordinated care.</b></p> <ul data-bbox="316 1258 1881 1343" style="list-style-type: none"><li>• Providers should not just welcome data from other providers but from consumers and family caregivers as well.</li></ul>

## Section C: Cultural change for individuals including demanding and using their electronic health information, continued

Category	Comments
C3. Privacy and Security for Individuals	<p><b>1. <u>Call to action:</u> Public and private sector stakeholders should <u>assess</u> whether people understand how to safeguard their health information and the need for resources related to this topic.</b></p> <p>Call to action should go beyond assess and leverage knowledge about consumer awareness and privacy that is already known</p> <ul style="list-style-type: none"><li>• HIPAA notices are not adequate – policy gaps exist with respect to mobile apps and other technologies</li><li>• Need to educate consumers on safeguarding information in a new and rapidly evolving environment</li></ul> <p><b>2. <u>Call to action:</u> Providers should provide individuals with secure access to their own behavioral health information in a manner that is easy to use and enables them to make choices about disclosure of specific information that is sensitive to the individual and/or legally protected.</b></p> <ul style="list-style-type: none"><li>• Segmentation of data should include ANY data that patient feels is sensitive not just behavioral health</li></ul>

## Section C: Cultural change for individuals including demanding and using their electronic health information, continued

Category	Comments
C4. Education and digital health literacy for individuals	<p><b><i>1. Call to action: Consumer advocacy groups in collaboration with government agencies, associations and payers should develop and disseminate resources (toolkits and best practices) based on consumer needs to assist individuals with increasing their digital health literacy. This supports consumer participation in shared decision making with their care team based on more complete and accurate information</i></b></p> <ul style="list-style-type: none"><li>• Health literacy and digital literacy are national problems should be addressed on a national scale by Federal government in partnership with consumer advocacy groups. Federal government must develop comprehensive strategy, tools and resources for all stakeholders.</li></ul> <p><b><i>4. Call to action: ONC and the industry should work with individuals to ensure that a majority understand the value of sustained engagement in managing their health, supported by health IT.</i></b></p> <ul style="list-style-type: none"><li>• Should be part of an overall communication strategy to help individual understand privacy and security and the value of health IT</li><li>• Ongoing “patient engagement” initiatives, and the Interoperability Roadmap should focus on enabling the technology to support consumer, family caregiver and provider partnerships in the achievement of shared health and care goals</li></ul>



# Specific Comments on Section D



## Section D: Care Providers Partner with Individuals to Deliver High Value Care

### General Comments

- Section D should be revised to better emphasize the clinical-patient –family partnership.
- Section is very provider focused, even in sections where consumers and families have an important role to play (example: Governance)
- Section D is potentially overwhelming; providers report being overwhelmed with requirement today (MU, PQRS, ICD 10, etc.)

Overall we suggest:

- Focus more on outcomes and less on process.
- Combining this with Section C could also help

# Section D: Care Providers Partner with Individuals to Deliver High Value Care, continued

Category	Comments
<b>D2. Providers embrace a Culture of Interoperability and work with vendors and other supporting entities to improve interoperability</b>	<p><b>1. Call to action: Providers should routinely expect electronic access to outside information in the provision of care and engage with other providers to send, receive, find and use health information for their patients.</b></p> <ul style="list-style-type: none"><li>• <u>New call to action:</u> Vendors should build tools and interfaces that make all relevant information, including information from patients and other providers, easy to digest and act upon for providers, so it becomes a seamless part of their workflow.</li><li>• Develop tools that make data actionable for providers</li></ul> <p><b>2. Call to action: Providers should recognize that valuable clinical information about their patients may reside with patients or caregivers themselves and that they may need to incorporate that information into their decision making.</b></p> <ul style="list-style-type: none"><li>• Strongly support this concept. However, must be focused on enabling providers to efficiently use data – not just encouraging them to “value it.”</li><li>• If data is valuable and easy to use providers will use the data</li></ul>

# Section D: Care Providers Partner with Individuals to Deliver High Value Care, continued

Category	Comments
<b>D2. Providers embrace a Culture of Interoperability and work with vendors and other supporting entities to improve interoperability</b>	<p><b><i>4. Call to action: Providers and their organizations should ensure contracts and agreements that they sign and re-sign with technology developers include necessary requirements for interoperability, to ensure they can share and incorporate patient information</i></b></p> <p>Need to remove barriers to ensuring sharing and incorporation of patient information such as excessive fees charged by vendors for building interfaces and additional fees for data to flow through the interfaces</p> <p><b><i>8. Call to action: Providers and their organizations should work with necessary parties to configure systems so that the presentation of information to providers is configurable based on use case, provider specialty and other characteristics, to facilitate usability and patient safety.</i></b></p> <p>Priority use case: Bi-directional, dynamic person-centered planning oriented around share health and care goals supporting care coordination, person and family engagement and interoperability</p>

# Section D: Care Providers Partner with Individuals to Deliver High Value Care, continued

Category	Comments
<b>D2. Providers embrace a Culture of Interoperability and work with vendors and other supporting entities to improve interoperability</b>	<p><b>10. Call to action: Providers should routinely use and have access to robust and clinically relevant decision support (e.g. for medication management).</b></p> <p>Progress should be made towards integrating shared decision making tools with clinical decision support</p> <p><b>12. Call to action: Providers should receive and provide continuous feedback to support the improvement of decision-making, care processes and outcomes. ( 2021 -2024)</b></p> <p>If providers have started doing this in the previous time period, and quality measures and payment are aligned, this will be the natural outcome and may not require a separate call to action.</p>

# Section D: Care Providers Partner with Individuals to Deliver High Value Care, continued

Category	Comments
<p><b>D 3. Accurate Measurement</b></p>	<ol style="list-style-type: none"> <li><b>1. Call to action: Providers should leverage data beyond their internal systems for population health analytics and quality measurement</b></li> <li><b>2. Call to action: Providers and other stakeholders should use standard metrics of interoperability to monitor and track improvement.</b></li> <li><b>5. Call to action: Public and private stakeholders should objectively measure and value interoperability and information sharing as an indicator of care coordination, quality and efficiency.</b></li> </ol> <p>WG supports these essential calls to action. Suggest the following:</p> <ul style="list-style-type: none"> <li>• Government should invest in development of more advanced eCQMs. Include harmonizing quality, population health, MU common data set, consumer information technology(2015-2017)</li> <li>• Focus on the purpose of interoperability – develop measures for care-coordination, communication and health outcomes instead of measuring interoperability (2018-2020)</li> <li>• Payment for outcomes that require interoperability – like robust care coordination, person-centered planning, eVisits, reduction in duplicative testing etc.</li> <li>• Government must outline a strategy for revision of current measure sets, new payment approaches to incentive performance</li> </ul>
<p><b>D 4. Interoperability of processes and workflow</b></p>	<p>Suggest re-evaluating this section entirely. Focus on managing workflows may not be needed if, per the previous section, progress has been made in advancing measurement and payment.</p>

## Section D: Care Providers Partner with Individuals to Deliver High Value Care

Category	Comments
D 5: Training and maintenance of certification for providers	Workgroup is not commenting on this section
D 6. Innovation and Generation of New Knowledge and Evidence	<p data-bbox="305 536 1899 665"><b><i>1.Call to action: Providers currently engaged in clinical research and quality improvement should work together with research institutions and other public and private stakeholders to establish a strategic plan for research and the generation of new knowledge.</i></b></p> <p data-bbox="305 718 1528 758">This call to action should include patients, families and their advocates</p> <p data-bbox="305 819 707 859"><b><u>Overarching Comment</u></b></p> <p data-bbox="305 921 1885 1079">Given the large amount of federal funds dedicated to research, and the importance of federal funds and policy in promoting innovation, there should be a clearer role articulated for government.</p>

# Section D: Care Providers Partner with Individuals to Deliver High Value Care, continued

Category	Comments
D 7. Transparency of Value and engagement of patients families and caregivers	<p><b>1. Call to action: Providers should work together with purchasers of care to have access to patient out-of-pocket costs and those of payers and purchasers. Providers are engaged in regional efforts to measure quality and maximize value.</b></p> <p>Patients, families and their advocates should also be engaged in regional efforts to measure quality and maximize value.</p> <p><b>4. Call to action: Providers should routinely utilize cost and quality data to make shared diagnostic and treatment planning decisions.</b></p> <ul style="list-style-type: none"><li>• Clarify- Shared decision <u>with</u> patients and families.</li><li>• Consumers must be at the table to design the process, particularly where cost and quality data are involved. Cost focus can be risky if done without consumer involvement.</li></ul> <p><b>5. Call to action: Providers should work together with purchasers of care to develop, test and implement appropriate and credible indicators of value.</b></p> <ul style="list-style-type: none"><li>• Harmonize with Section D3 (earlier section on quality and measurement)</li><li>• Federal investment needed to create credible, meaningful measures of value</li></ul>

## Section D: Care Providers Partner with Individuals to Deliver High Value Care, continued

Category	Comments
<b>D 7.</b> Transparency of Value and engagement of patients families and caregivers	<p><b>6. Call to action: Providers should support consumer-facing services such as:</b></p> <ul style="list-style-type: none"><li><i>o Online scheduling</i></li><li><i>o Medication refill requests</i></li><li><i>o Electronic/Telehealth Visits</i></li><li><i>o Patient provided device data, screenings and assessments</i></li><li><i>o Informed consent and education modules</i></li><li><i>o Integration of patient generated health data in the medical record</i></li><li><i>o Patient-defined goals of care</i></li><li><i>o Shared care planning</i></li></ul> <ul style="list-style-type: none"><li>• Timeline should be earlier than 2018-2020; especially for those included in MU2</li><li>• eVisits, telehealth and devices needed much more work and can be separated compared to the other areas</li><li>• Recommend this amended call to action be integrated with Section C</li></ul> <p><b>8. Call to action: Providers and individuals should work together to substantially reduce the burden of care coordination through patient-centered tools and sharing and use of electronic health information.</b></p> <p>A measure of the outcome would be more appropriate here – that care is actually more coordinated, high-value, and patient- and family-centered.</p>





# Questions