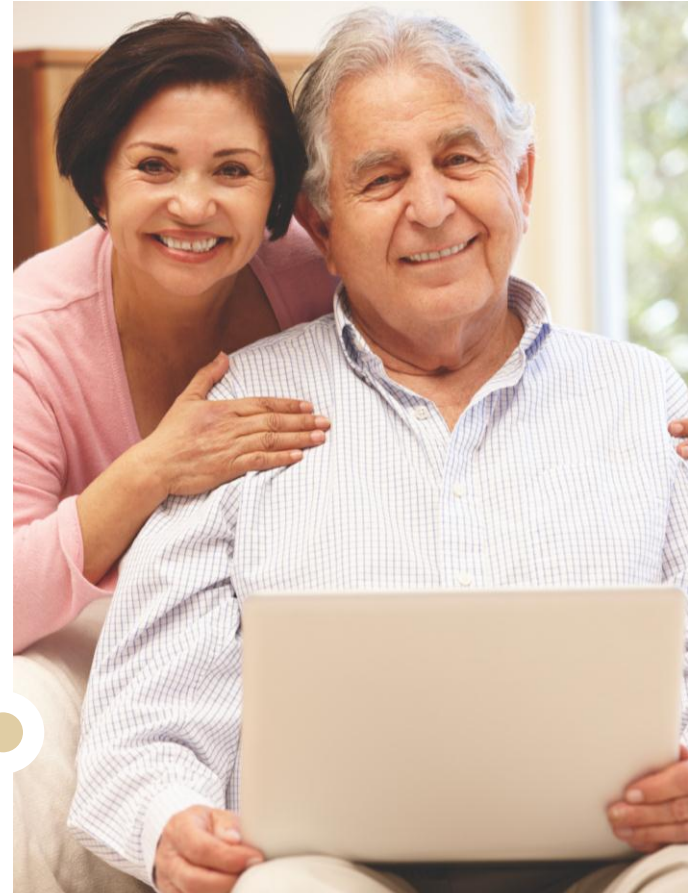


# Leveraging Meaningful Use to Reduce Health Disparities: An Action Plan

FEBRUARY 10, 2014



Consumer  
Partnership  
for **eHealth**

# About Us



- **National Partnership for Women & Families**
  - Non-profit, consumer organization with 40 years' experience working on issues important to women and families.
    - Health and care, workforce, anti-discrimination
- **Consumer Partnership for eHealth**
  - More than 50 consumer organizations advancing health IT in ways that benefit patients and families.
  - *Making IT Meaningful: How Consumers Trust & Value Health IT*
    - In-depth survey detailing consumer experience with both electronic and paper medical record systems.
  - *Leveraging Meaningful Use to Reduce Health Disparities: An Action Plan*
    - Evidence-based action plan for leveraging the EHR Incentive Program to reduce health disparities and make a positive life-altering impact for the nation's underserved and vulnerable populations.
  - *Care Plans 2.0: Consumer Principles for Health & Care Planning*
    - High-level principles articulating what consumers want and need to manage their health, and how to leverage health IT to plan and communicate more effectively in healthcare.

# Winter **Webinar** Series



- **Virtual Open House: Patient- & Family-Centered Health IT**
  - [Jan. 21 Webinar Recording Available](#)
- **Meaningful Use 101: Back to Basics**
  - [Feb. 5 Webinar Recording Available](#)

# The Collaborators



As consumer advocates on behalf of some of our most underserved populations, we are dedicated to ensuring increased health equity, access, and quality for all populations, regardless of race, ethnicity, sex, gender, sexual orientation, gender identity, language access, socio-economic status, or physical, cognitive, mental and other disabilities. We are partnering to lend our collective voices and expertise to an action plan that fills existing gaps and helps empower our nation's most vulnerable populations.



California Pan-Ethnic Health Network



American Association on Health and Disability



Disability Rights Education & Defense Fund



American Heart Association®

Learn and Live

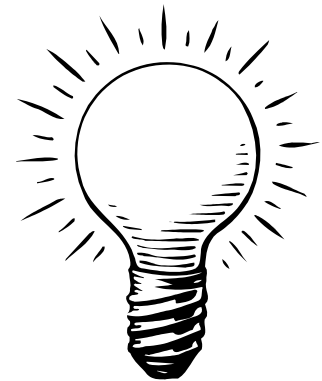
# The Very **Personal** Cost of Health Disparities



- From 2003 to 2005, an African-American child with asthma was seven times more likely to die from it than a white child.<sup>1</sup>
- Nearly half of Spanish-speaking Hispanics reported having trouble communicating with their doctors.<sup>2</sup>
- One in five Spanish-speaking Latinos reported not seeking medical care because of language barriers.<sup>3</sup>
- In 2003, 25 percent of African-American children lacked one or more of the most current immunizations, as compared to 16 percent of white children.<sup>4</sup>
- In 2010, only 68 percent of Asian-American women over the age of 18 had a Pap test, as compared to white women (72.8 percent), African-American women (77.4 percent), and Latino women (73.6 percent).<sup>5</sup>

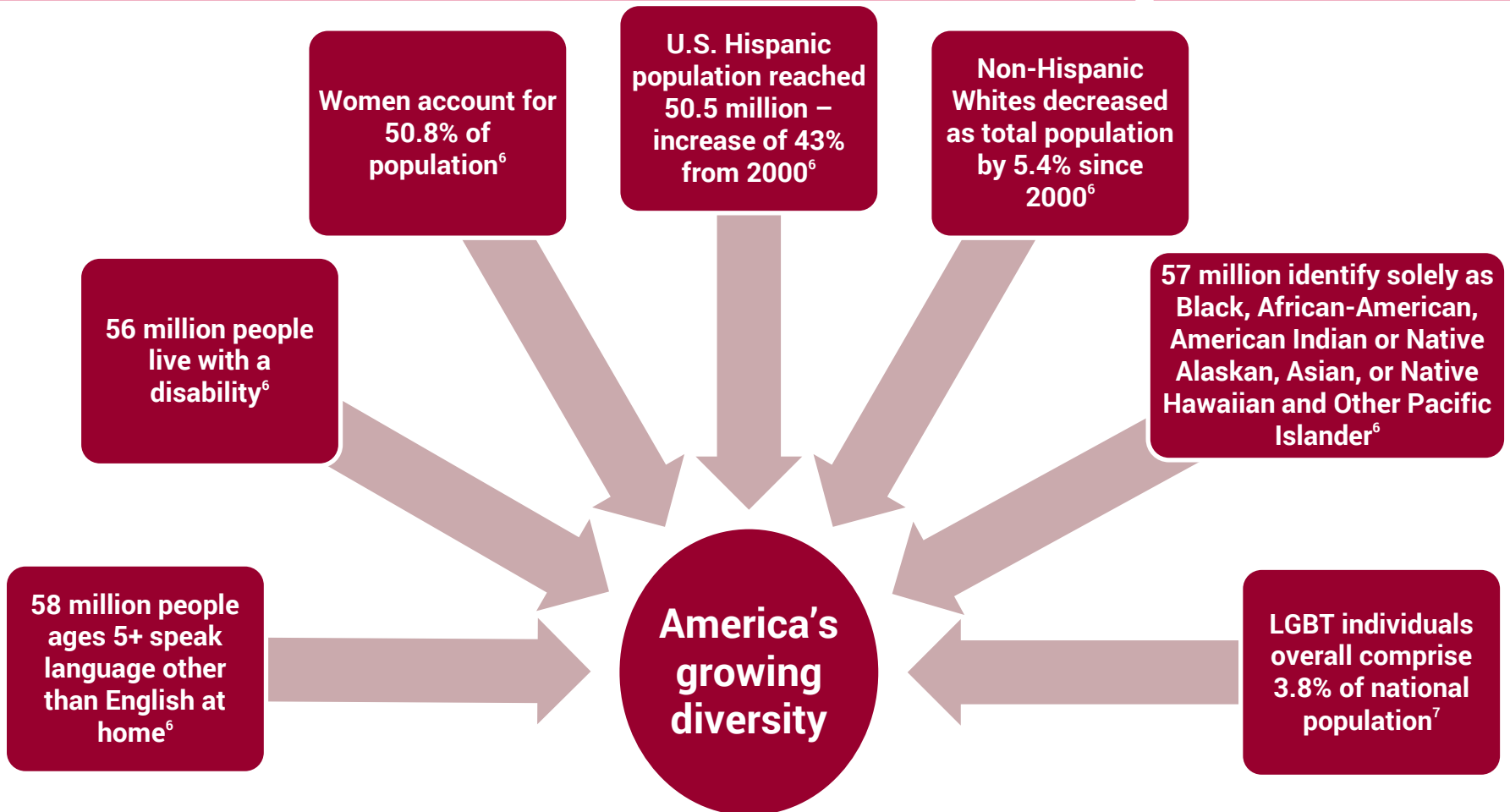
# The **Vision**

**We envision design and robust use of secure health information technology nationwide that redresses existing disparities, avoids creating new disparities, and improves health care, services, and supports for vulnerable populations. Ensuring that health IT improves health care first and foremost for these individuals will translate to improvements for everyone, including patients, family and other caregivers as appropriate, and practitioners. We believe the “Meaningful Use” EHR Incentive Program offers a significant, unprecedented opportunity to reduce health disparities by addressing not only the multi-faceted needs of individuals and groups, but also the overlapping needs of all populations. To date, this potential has not been fully realized, and it is an opportunity we cannot afford to squander.**



# The Opportunity

EQUALITY

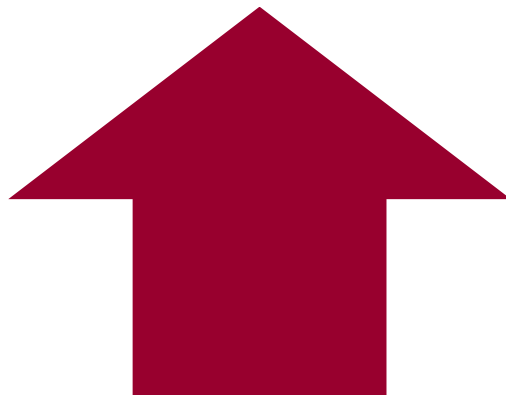
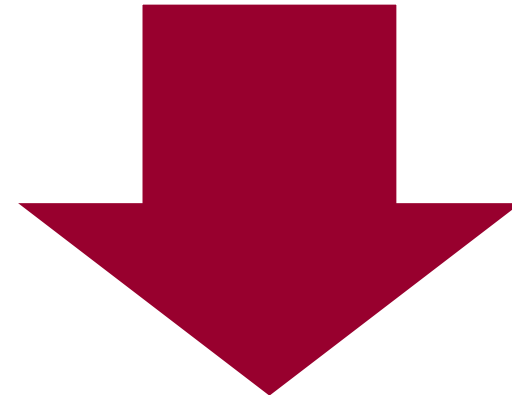




# Health Disparities and **Health IT**



**The combined costs of health disparities and premature death in the United States were \$1.24 trillion, from 2003 to 2006.<sup>8</sup>**



**Health IT can reduce health disparities by increasing individuals' access to their own health information and improving communication between providers and patients.**



# Health Disparities in **HITECH**



## **“SEC. 3001. OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY.**

**“(a) ESTABLISHMENT.—**There is established within the Department of Health and Human Services an Office of the National Coordinator for Health Information Technology (referred to in this section as the ‘Office’). The Office shall be headed by a National Coordinator who shall be appointed by the Secretary and shall report directly to the Secretary.

**“(b) PURPOSE.—**The National Coordinator shall perform the duties under subsection (c) in a manner consistent with the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information and that—

**“(1) ensures that each patient’s health information is secure and protected, in accordance with applicable law;**

**“(2) improves health care quality, reduces medical errors, reduces health disparities, and advances the delivery of patient-centered medical care;**

**“(3) reduces health care costs resulting from inefficiency, medical errors, inappropriate care, duplicative care, and incomplete information;**

**“(4) provides appropriate information to help guide medical decisions at the time and place of care;**

**“(5) ensures the inclusion of meaningful public input in such development of such infrastructure;**

**“(6) improves the coordination of care and information among hospitals, laboratories, physician offices, and other entities through an effective infrastructure for the secure and authorized exchange of health care information;**

**“(7) improves public health activities and facilitates the early identification and rapid response to public health threats and emergencies, including bioterror events and infectious disease outbreaks;**

**“(8) facilitates health and clinical research and health care quality;**

**“(9) promotes early detection, prevention, and management of chronic diseases;**

**“(10) promotes a more effective marketplace, greater competition, greater systems analysis, increased consumer choice, and improved outcomes in health care services; and**

**“(11) improves efforts to reduce health disparities.**



# Progress to Date



- **Stages 1 and 2 of the MU functional criteria require providers to record a patient's demographic information and to generate at least one list of patients by specific condition to use for quality improvement, reduction of disparities, research, or outreach.**
  - **However, there is no requirement to view lists of patients by disparity variables such as race, ethnicity, language, gender identity, sexual orientation, socio-economic status, or disability status.**
  - **Moreover, neither stage require additional criteria to explicitly identify, report, address, and reduce health disparities.**

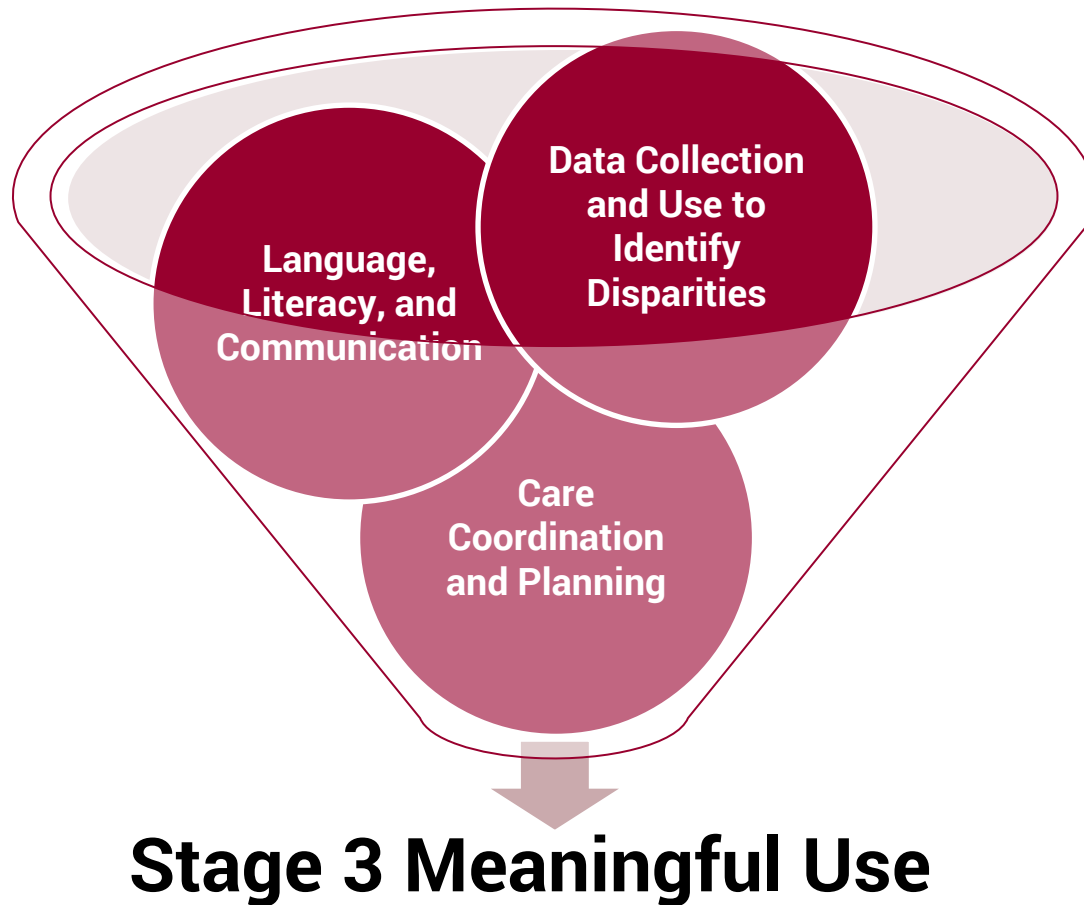
# Literature Review



- **Several overarching themes emerged:**
  - Encouraging and maximizing use of data to drive care delivery;
  - Making information meaningful and useful to members of underserved populations;
  - Connecting individuals, healthcare providers, and communities; and
  - Ensuring equitable impact of state and federal health IT investments.
- Literature review available [here](#).



# Areas of **Focus** for Stage 3





# Data Collection **Standards**



2009 IOM report recommended even more granular data collection that is too far of a leap for current CEHRT, but should be our guiding light.<sup>10</sup>



Should advance to HHS standards, building upon OMB standards, but adding the type of granularity for Asian and Latino populations that is used in the American Community Survey and Decennial Census.



Currently, data collection capabilities of ONC-certified EHRs are based on OMB-created standards.

# OMB Standards for Race and Ethnicity



## OMB Standards<sup>11</sup>

**White**

**Black or African-American**

**Hispanic or Latino**

**Asian**

**Native Hawaiian or other  
Pacific Islander**

**American Indian or Alaskan  
Native**



# HHS Standards for Race and Ethnicity



Part of Current OMB Standards	Latino/Hispanic Category	Asian Category	Native Hawaiian or Other Pacific Islander Category <sup>11</sup>
White	Not of Hispanic, Latino/a, or Spanish origin	Asian Indian	Native Hawaiian
Black or African American	Mexican, Mexican American, Chicano/a	Chinese	Guamanian or Chamorro
American Indian or Alaska Native	Puerto Rican	Filipino	Samoan
	Cuban	Japanese	Other Pacific Islander
	Another Hispanic, Latino, or Spanish origin	Korean	
		Vietnamese	
		Other Asian	



# Why the **Granularity**?



- **Different ethnic groups have vastly different health profiles**
  - 22 percent of Korean adults versus 7 percent of Chinese adults are smokers.<sup>12</sup>
  - Asian Indian adults are nearly three times more likely to have diabetes than Japanese-Americans, but are less likely to have hypertension.<sup>13</sup>
  - Puerto Ricans and Hispanics living in the Southwest have higher rates for type 2 diabetes than Cubans.<sup>14</sup>
- ***Even within one medical practice, when data are grouped together and averaged, variations are obscured.***

# Data Collection Standards on **Disability**



- **HHS has established standards for the collection of information on disability status.<sup>15</sup>**
  - Define disability “from a functional perspective.”
  - Meant to serve as a baseline.

## **HHS Data Standards for Disability Status**

**Are you deaf or do you have serious difficulty hearing?**

**Are you blind or do you have serious difficulty seeing, even when wearing glasses?**

**Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old and older)**

**Do you have serious difficulty walking or climbing stairs? (5 years old and older)**

**Do you have difficulty dressing or bathing? (5 years old and older)**

**Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? (15 years old and older)**

# Data Collection Standards on **Sexual Orientation** and **Gender Identity**



- **An IOM workshop on SOGI data collection in EHRs found that many health care facilities are already recognizing the LGBT individuals in their patient populations and implementing efforts to collect and safeguard important sexual orientation and gender identity data in their patient records systems.<sup>16</sup>**
  - **For example the Fenway Institute completed extensive studies on this matter and has published information on how to gather SOGI data in clinical settings, available [here](#).<sup>17</sup>**
- **Moreover the development of more granular data collection standards for race, ethnicity, sex, language, and disability status was required under section 4302 of the ACA for the purpose of data collection in all federal surveys.<sup>18</sup>**
  - **As we continue to reform our health care delivery system, it is imperative that the EHRs are adapted to use the same data collection standards.**

# Data **Stratification** and **Reporting** and **CDS**



- **Data stratification and reporting**
  - Stratifying patient data by disparity variables may alert providers to disparities in health outcomes among their patient populations that they might not have known.
  - Stratifying reported quality measures by at least two disparity variables, with reduction in disparities demonstrated in at least one measure would build on the quality measure requirements of Stages 1 and 2 of Meaningful Use.
- **Data collection for clinical decision support (CDS)**
  - CDS offers automated decision-making assistance at the point of care by arming providers with tools such as condition-specific order sets, clinical guidelines, and diagnostic support.
  - *However, these tools require person-specific data.*
  - Example: transgender patients<sup>19</sup>

# Bridging the **Digital Divide**



- **Smartphones can collect patient-generated health data (PGHD) through mobile health apps.**
- **As smartphones are also bridging the digital divide, they provide an important point of health care access to underserved communities.**<sup>20</sup>
- ***Data collection should not solely be restricted to examination rooms.***

## Who owns smartphones<sup>21</sup>

*% of American adults within each group who have a smartphone*

<b>All adults (n=3,014)</b>	<b>45%</b>
Men (n=1,337)	46
Women (n=1,677)	45
<b>Age</b>	
18-29 (n= 478)	66
30-49 (n=833)	59
50-64 (n=814)	34
65+ (n=830)	11
<b>Race/ethnicity</b>	
White, Non-Hispanic (n=1,864)	42
Black, Non-Hispanic (n=497)	47
Hispanic (n=427)	49

Source: Pew Research Center's Internet & American Life Project, Summer Tracking Survey, August 7-September 6, 2012. N=3,014 adults ages 18 and older. Interviews were conducted in English and Spanish and on landline and cell phones (1,206 cell calls were completed). Margin of error is +/- 2 percentage points.

# Data Collection and Use to Identify **Disparities**



## Data Collection and Use to Identify Disparities

### Stage 3 RFC Criteria ID Numbers

**Stage 3:** EHRs should accommodate collection of more granular data on patients' race, ethnicity, and language by using HHS standards rather than OMB standards, and moving toward the eventual approach recommended by the Institute of Medicine

104

**Stage 3:** EHRs should enable and incentivize new types of data collection, such as sexual orientation; gender identity; occupation and industry codes; and physical, behavioral, and cognitive disability

104, 113

**Stage 3:** The population health dashboard should include views of patient populations across multiple disparity variables, even if certain objectives related to recording disparity variables are retired

104, 108, 109, 112, 113, 115, 119

**Stage 3:** Reported quality measures should be stratified by at least two disparity variables, with reduction in disparities demonstrated in at least one measure

All CQMs

# Data Collection and Use to Identify **Disparities** Cont.



## Data Collection and Use to Identify Disparities

### Stage 3 RFC Criteria ID Numbers

***Stage 3:*** EHRs should capture patient preferences with regard to sharing their health information for research purposes.

104

***Stage 3:*** Patient experience data should be collected in patients' preferred language and/or alternative formats that accommodate disabilities. Providers should use anonymized results to improve care delivery.

204B, 304

***Stage 3:*** Care summaries and plans should require recording of caregiver status and roles using DECAF standards (Direct care provision, Emotional support, Care coordination, Advocacy, and Financial) as appropriate.

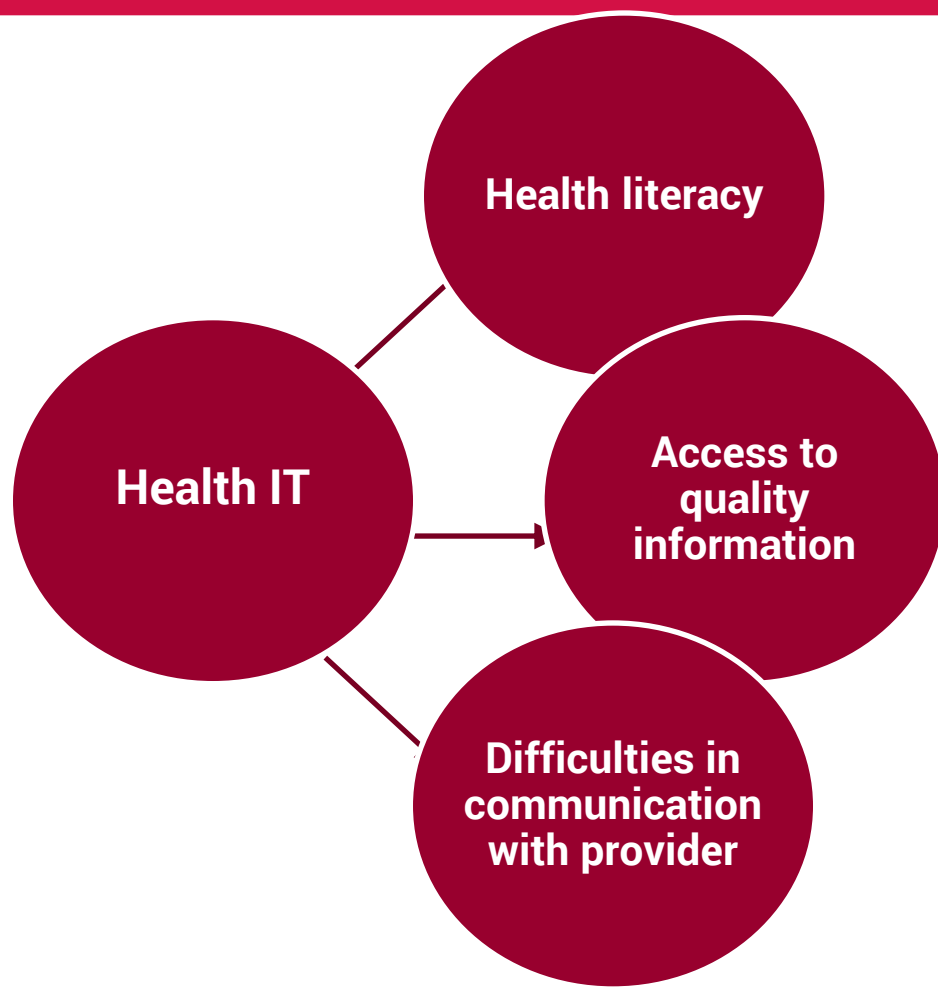
303

***Stage 3:*** EHRs should incorporate data collection and real-time integration from home monitoring devices, including apps and smart phones.

204A, 204B, 207, 304

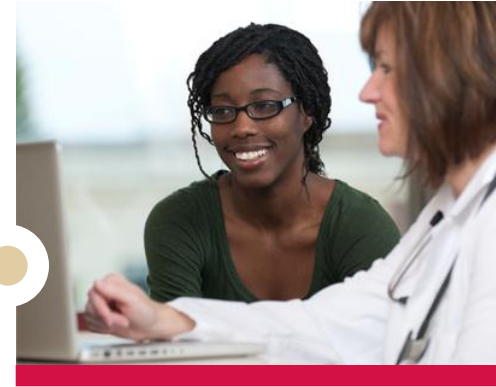


# Language, Literacy, and **Communication**



**HOWEVER...**

# Language, Literacy, and **Communication**



- **All electronic health information must be available in:**
  - **Human readable and useable formats, (including appropriate health literacy and numeracy levels);**
  - **Languages in addition to English; and**
  - **Formats appropriate for individuals with visual, hearing, cognitive, and communication impairments and physical disabilities.**
- **Doing so is directly aligned with National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care.<sup>22</sup>**

# Language, Literacy, and **Communication**



- **Patient education and health information**
  - Consumer access to their health information through V/D/T and Blue Button
  - Patient education materials
- **Communication platforms**
  - Bi-directional communication and patient-generated health data
- **Patient-provider communication**
  - Secure messaging, reminders, and consumer feedback



# Language, Literacy, and **Communication**



## Language, Literacy and Communication

### Stage 3 RFC Criteria ID Numbers

***Stage 3:*** All patient-facing information and decision support tools should be displayed in no higher than 6th-8th grade reading level, in patients' preferred languages, and accessible to those with visual, hearing, cognitive, and communication impairments

105, 204A, 204B, 204D, 205, 206, 207, 208, 303, 304, 127, 308

***Stage 3:*** EHRs and online access for patients should incorporate automatic links translating medical jargon to contextual information accessible to patients and displayed in no higher than 6th-8th grade reading level, in patients' preferred languages, and accessible to those with visual, hearing, cognitive, and communication impairments

204A, 204B, 204D, 205, 206, 207, 303, 304, 127

***Stage 3:*** V/D/T and Blue Button function should include information displayed in patients' preferred languages and accessible to those with visual, hearing, cognitive, and communication impairments

204A, 204B, 204D, 208

# Language, Literacy, and **Communication** Cont.



<b>Language, Literacy and Communication</b>	<b>Stage 3 RFC Criteria ID Numbers</b>
<b><i>Future Stages:</i></b> EHRs should facilitate patient tutorials on use of systems (such as online access) with built-in explanations of individual functions and features (via hover box) and videos in patients' preferred languages and accessible to those with visual, hearing, cognitive, and communication impairments	204A, 204B, 205, 206, 207, 208, 303, 304, 127
<b><i>Future Stages:</i></b> Patient-interfaces (such as texting and smartphone platforms, patient portals, patient reminders and secure messaging, etc.) should be able to accommodate patients' linguistic, visual, hearing, and/or cognitive needs	105, 116, 204A, 204B, 204D, 205, 206, 207, 208, 303, 304, 127, 308

# Care **Coordination** and **Planning**



- **Underserved populations and members of racial and ethnic minority groups often suffer from lack of care coordination more acutely than the general population.** <sup>23,24</sup>
- **Health IT systems should contain a range of information about patient support systems, including chosen family members, friends, and other key supports alongside individuals designated by state next-of-kin laws, as it is an important part of care coordination and planning.**
  - **While this information is sometimes captured in advance directives, many people – particularly members of marginalized populations – do not have advance directives.**

# Care **Coordination** and **Planning**



- **Care plans offer a place for communication and coordination between not only patients, caregivers, and providers, but also community entities offering services and supports.** <sup>25,26</sup>
- **Individuals experiencing health disparities often have difficulties accessing the supports and resources necessary to be active and engaged in their own health and health care.**
  - **Health IT could be used to connect people, their providers and the community resources that support them, as well as to coordinate efforts among them in ways that support health.**

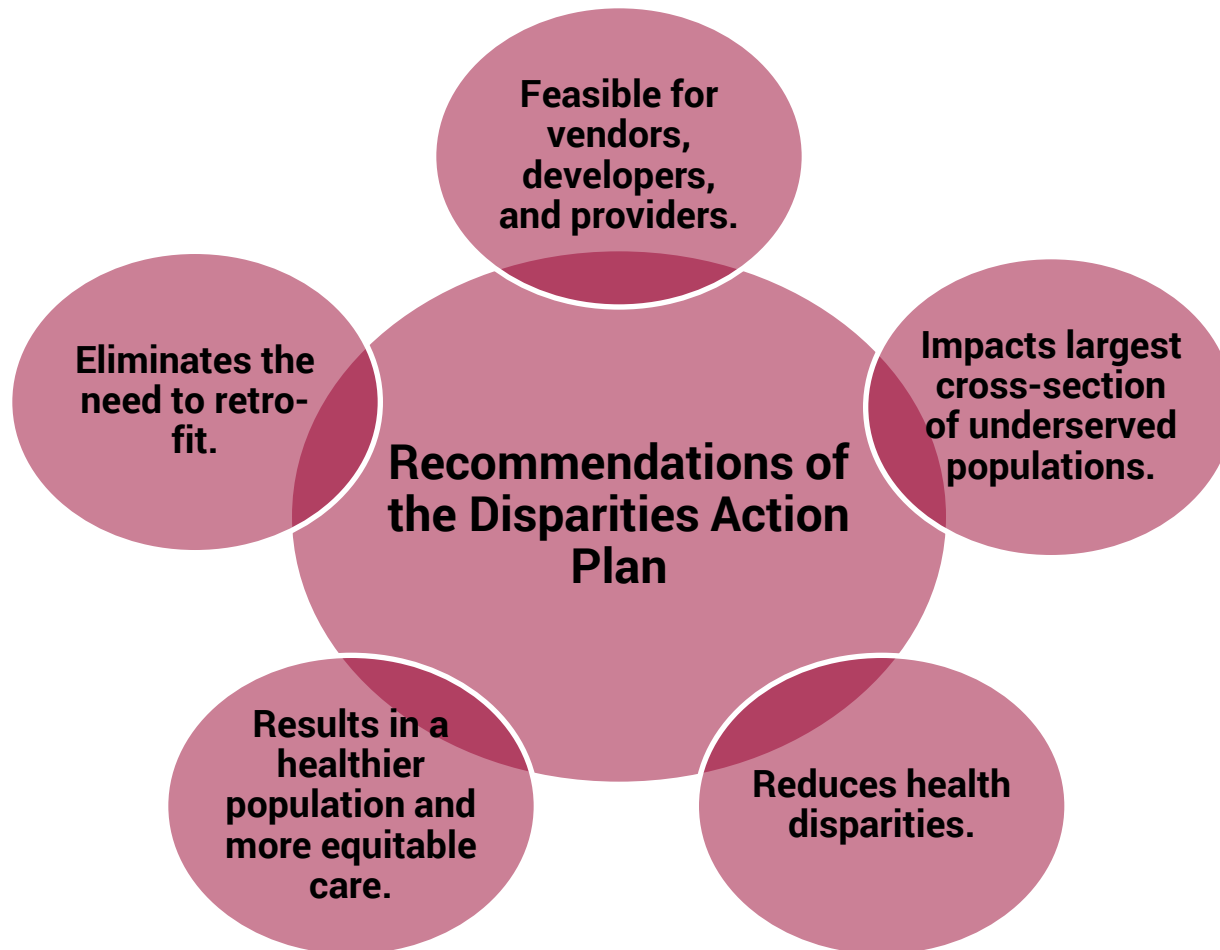


# Care **Coordination** and **Planning**



<b>Care Coordination and Planning</b>	<b>Stage 3 RFC Criteria ID Numbers</b>
<b><i>Stage 3:</i></b> Care plans should enable patient access and ability to contribute and correct health information (such as family health history, goals, chosen support individuals and networks, and advance directive content) to help manage their care and wellbeing	112, 119, 204A, 204B, 204D, 205, 303, 304
<b><i>Stage 3:</i></b> EHRs should have capacity for real time clinical trial identification and eligibility checking	209
<b><i>Stage 3:</i></b> Blue Button functionality should be implemented for Medicaid and CHIP beneficiaries	204A
<b><i>Future Stages:</i></b> EHRs should enable identification of community-based programs/supports from which patients may benefit, including by accessing an automated directory of community resources	108, 109, 113, 115, 206, 303, 304, 305

# The Path **Forward**



# The Complete **Report**



- The complete Disparities Action Plan report, including a detailed chart of Stage 3 and Future Stage recommendations can be found [here](#).

**“Every American  
deserves an  
equal chance at a  
full, healthy life.”**

– Debra Ness  
National Partnership  
for Women & Families

LEARN MORE: [NATIONALPARTNERSHIP.ORG/DISPARITIES](http://NATIONALPARTNERSHIP.ORG/DISPARITIES)

## Leveraging Meaningful Use to Reduce Health Disparities

AN ACTION PLAN

August 2013



**CP**  
**eH** Consumer  
Partnership  
for **eHealth**

# Media Mentions



- [NPWF Press Release](#)
- [Blog Post from Debra L. Ness, NPWF President](#)
- [Blog Post from Erin Mackay, NPWF Associate Director of HIT Programs](#)

<a href="#">Stage 3 MU must tackle care disparities</a> , Healthcare IT News	<a href="#">Will Stage 3 Meaningful Use help reduce health disparities?</a> , EMR Industry
<a href="#">Leveraging Health IT To Reduce Health Disparities</a> , Healthcare Technology Online,	<a href="#">Is Meaningful Use Stage 3 The Perfect Opportunity to Tackle Health Disparities?</a> , HIT Consultant
<a href="#">Consumer Groups Call for Meaningful Use Program to Address Health Disparities</a> , Bloomberg BNA	<a href="#">Health IT Policy Committee urged to consider care disparities</a> , PhysBizTech
<a href="#">Coalition's plan focuses on reducing health IT disparities</a> , Clinical Innovation+Technology,	<a href="#">Stage 3 Meaningful Use Should Address Care Disparities</a> , ChartLogic,
<a href="#">Consumer coalition proposes disparities reduction plan for Stage 3</a> , Government Health IT	<a href="#">Will Stage 3 Meaningful Use help reduce health disparities?</a> , Journal of the Student National Medical Association
IT needs to target health disparities, consumer groups say, Modern Healthcare	<a href="#">Will Stage 3 Meaningful Use help reduce health disparities?</a> , EHR Intelligence
<a href="#">MU3 Recommendations for Reducing Health Disparities Released by Consumer Coalition</a> , Becker's Hospital Review,	<a href="#">US: Consumer coalition proposes disparities reduction plan for Stage 3</a> , The Potsdam eGovernment Competence Center
<a href="#">A DISPARITY REDUCTION PLAN FOR MU3</a> , HIEWatch	<a href="#">Health disparities to be tackled in Meaningful Use Stage 3</a> , e-Prescribing Blog
<a href="#">Rethinking Stage 3 Meaningful Use to address key care disparities</a> , NueMD	<a href="#">Meaningful Use Stage 3 Should Address Care Disparities</a> , EMR & EHR
<a href="#">Coalition: Meaningful Use Stage 3 Must Focus on Care Disparities</a> , iHealthBeat	➔ The iHealthBeat story on the Disparities Action Plan was the third most popular in views and fourth most popular in email forwards.

# The Impact



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"According to the Institute of Medicine, collecting sexual orientation and gender identity data in electronic health records is crucial to understanding and addressing the health disparities that affect the lesbian, gay, bisexual, and transgender (LGBT) population. The Disparities Action Plan is a key step in turning that recommendation into action to finally end the culture of 'don't ask, don't tell' for LGBT people in our healthcare system." **Kellan Baker**, Center for American Progress.

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"Health information technologies must integrate and use all health care and related community services and support strategies and tools to overcome health disparities faced by persons with all types of disabilities. The Action Plan incorporates these necessary strategies and tools, and thus has great potential to overcome disparities." **Clarke Ross**, American Association on Health and Disability.

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"This action plan presents a great opportunity to improve quality of care, enhance patient participation and understanding, and reduce health disparities nationwide through health information technology. It is important that we implement these recommendations so that the health disparities of today are not replicated in electronic health systems tomorrow." **Kathy Ko Chin**, Asian & Pacific Islander Health Forum.

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"The Action Plan is a guide to improving the health quality of low-income populations, communities of color, women, individuals with limited English proficiency, and other underserved communities. It serves as the missing link that connects the mission of the HITECH Act with existing laws, HHS strategies, and advocacy efforts that support health equity." **Deborah A. Reid**, National Health Law Program.

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"Health IT holds the promise to increase access to health care information; however, such access will not be possible for many people with disabilities unless accessibility features are built into health information systems from the beginning. For health care providers, ready access to disability status information is also critical. This Action Plan presents well-crafted, detailed recommendations for reaching these goals." **Rhonda Neuhaus**, Disability Rights Education and Defense Fund.

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"It's impossible to achieve better health outcomes and significantly reduce health care costs without tackling health disparities, which are a pervasive and costly problem. We have the chance to leverage Stage 3 of the Meaningful Use program to make significant progress in addressing disparities. We must not squander this opportunity. CPeH has created a bold, yet achievable, path forward for including criteria in Stage 3 that will begin to reduce disparities and, in doing so, help us achieve patient- and family-centered care, better outcomes, and lower costs for everyone." **Debra L. Ness**, National Partnership for Women & Families.

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# For More **Information**



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# Join **Us!**



- **CPeH membership**
  - Consumer, patient, and labor advocates
  - Private and public sector *Friends of CPeH*
- **Variety of ways to contribute:**
  - Organization name
  - Time and expertise
  - Participation on committees and working groups
  - Sign-on to comment letters
- **Strength in numbers!**
  - Consumer needs and priorities should be reflected in health IT policies and practices
  - If you're interested in joining the Consumer Partnership for eHealth, email Erin at [emackay@nationalpartnership.org](mailto:emackay@nationalpartnership.org)





# Endnotes



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