White House Summit on Achieving eHealth Equity

Introduction: eHealth and Health Equity

In 2011, the U.S. Department of Health and Human Services (HHS) released two reports that further highlight the importance of using health IT to address health disparities among underserved communities. *The National Stakeholder Strategy for Achieving Health Equity* and *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* highlight how health IT can improve care quality and health outcomes within these communities.

Technology can be tailored to "meet people where they are" and therefore is a powerful tool in actually helping to achieve equity in health care. Despite concerns about the digital divide, a recent study found that age, education, and income levels are not accurate indicators of patients' willingness to adopt an electronic health (eHealth) tool, such as a personal health record.[1] Still, other studies demonstrate disparities in the adoption of such tools related to factors such as race, ethnicity, education, income, age, literacy, disabilities, geography, and others.[2, 3]

In February 2013, the U.S. Department of Health and Human Services Office of the National Coordinator for Health Information Technology (ONC), Office of Minority Health (OMH), and ZeroDivide convened a diverse group of stakeholders at the White House to discuss how to advance eHealth among the underserved and the role eHealth can play in achieving health equity.

Specifically, the summit objectives were to:

1. Establish an understanding of the current use of eHealth, as well as barriers to use of eHealth technologies among underserved and minority populations.

2. Identify "community champions" and "bright spots" that have demonstrated successful engagement of underserved patients and their family caregivers in the use of eHealth to improve access to health care, facilitate care coordination, and improve self-management of health conditions.

3. Identify opportunities for ONC, OMH, and its Federal partners to collaborate with industry and community leaders and grassroots organizations to prioritize several strategies that will promote patient engagement via eHealth while addressing barriers to eHealth equity.

In a roundtable format with active discussion, attendees shared ideas about increasing patient engagement using eHealth, identified opportunities to work collaboratively, and committed to taking individual action following the meeting. The White House Summit on Achieving eHealth Equity was followed by a webinar during which participants continued the dialogue and proposed specific action steps that are included in this briefing document.

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1. Noblin AM, Wan T, Fottler M. The impact of health literacy on a patient's decision to adopt a personal health record. Pers Health Inf Manag. 2012;(9):1e.
2. http://www.kpihp.org/kpihp/frmContent.aspx?CMS_Entry_Id=321&Content_Type=H
3. http://www.amia.org/sites/amia.org/files/Roundtable-Background-Paper-2011.pdf

Defining the Underserved

During the summit, participants discussed how the term "underserved" has evolved over time and that there is a common understanding that there is a need to clearly define the population if we are to create solutions that meet their needs. The participants discussed how racial and ethnic minorities are traditionally defined as "underserved," but the term has broadened to include seniors, the disabled, youth, Lesbian/Gay/Bisexual/Transgender community, and the incarcerated. In addition to health and healthcare considerations, "underserved" communities may also include those facing financial barriers, socioeconomic challenges, environmental hazards, or lack of access to natural resources such as clean water.

Current Use of eHealth and Ongoing Barriers Among Underserved and Minority Populations

> *We have seen tremendous advances in medicine and technology but the challenge is to reach everyone. We want to see opportunity for all people. There's no better time, especially with an administration that recognizes the importance of prevention and wellness, and that eliminating health disparities is fundamental for us to become a healthier nation in which everyone has the opportunity to reach their full potential for health.*
>
> Dr. J. Nadine Gracia
> Assistant Secretary, Office of Minority Health
> U.S. Department of Health and Human Services

In order to maximize the time together, participants completed a pre-summit survey and worked to define eHealth equity, and to better understand the current landscape of eHealth use in the context of health disparities. The group also explored current barriers to eHealth use and eHealth equity among underserved populations. These discussions are summarized below.
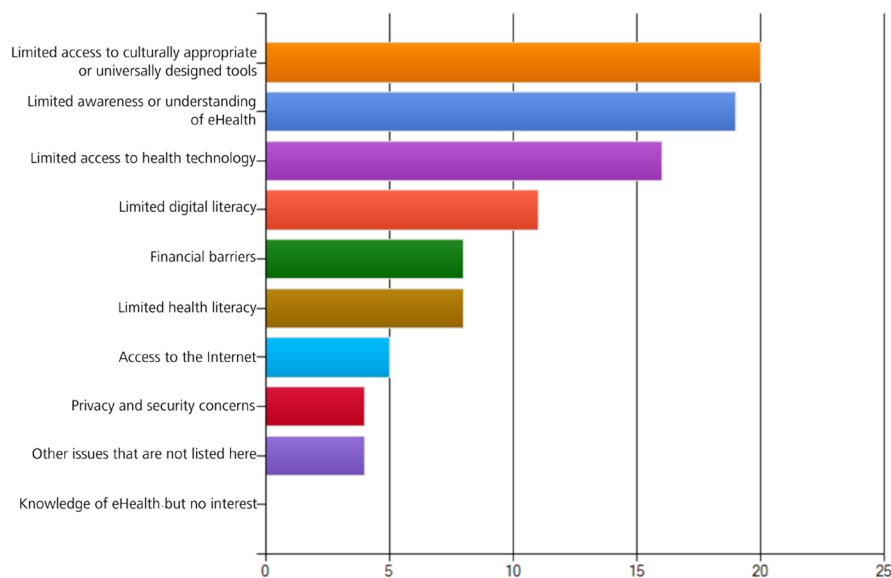
Top barriers to adoption of health information technology identified in pre-meeting survey (n=32).

Rural versus Urban Challenges

The barriers faced by underserved rural populations and those faced by inner-city populations may be more similar than they first appear. Noted one participant: "Even though one size doesn't fit all, it is possible that once we address the fundamental issue of access it will serve multiple populations. The question we need to ask is not how do we keep from bringing everyone down, but how do we bring everyone up to the same level? How do we engage, educate, and keep in touch with individuals, even when they are not seeking healthcare? Technology can help with that."

Lack of Outcomes Research

Research to this point has focused primarily on the impact of health IT on underserved communities in terms of access. More research is needed to examine how health IT has affected health outcomes among underserved populations. Electronic health records can enable researchers to more easily examine outcomes for specific populations.

Patient Engagement

Some see technology as a panacea, like the medical specialist who observed: "We use technology not just for information gathering and sharing, but for engagement." But as others noted, the trend towards greater patient engagement is not reaching everyone. As one participant articulated: "A lot of patients who are not in that traditionally underserved category are taking the lessons they've learned outside of healthcare to close the gap between being paternalistically led by providers to being engaged partners in their health. Yet that gap could get larger because one of the barriers [for underserved populations] is education."

Cultural Competence and Literacy

In many cases, literal language translation of material is the sole effort made towards meeting differing cultural and linguistic needs. Broader definitions of language and culture are needed, paired with approaches to communications and outreach that are easily customizable at the local level to meet local needs.

Access to Technology

Overall access to technology remains a serious concern among underserved populations, but this issue is more complex than it may first appear. For example, some underserved populations have high levels of access to sophisticated mobile technology, but may not have access to eHealth services optimized for those technologies.

Successes, Needs, and Opportunities

> *ONC's goal is to improve health and health care for all through the use of information technology. We have the opportunity and possibility with health information technology to tackle some of the most difficult problems by making visible what is often invisible in healthcare.*
>
> Dr. Farzad Mostashari
> National Coordinator, Office of the National Coordinator for Health IT
> U.S. Department of Health and Human Services

Moderators and participants brought several current examples to demonstrate the potential of eHealth to address health equity issues.

- Deputy Assistant Secretary for Minority Health, Dr. J. Nadine Gracia noted the success of electronic health records (EHR) within Federally qualified community health centers, and also described an "app challenge" launched by HHS as part of its efforts to reduce cancer among women of color.

- Dr. Mostashari, the National Coordinator, described the success of the Regional Extension Center (REC) program's efforts to target providers in underserved communities. Providers working with an REC were 2.3 times more likely to achieve meaningful use than providers that were not working with an REC.

- Another participant shared their experience developing an online portal about diabetes geared towards African Americans and their findings that eighth graders using the portal were able to use the information to educate their families and members of their wider community.

The roundtable discussions yielded additional specific needs and opportunities, summarized below.

Demonstrate Effectiveness

More rigorous studies are needed to document the effectiveness or ineffectiveness of eHealth tools. Demand for this research will only increase as patients, providers, hospital systems, and regulatory agencies attempt to use eHealth to improve performance, which is increasingly tied to payment

Create better tools

The overall quality of today's eHealth tools is decidedly mixed, and these quality issues have an impact on use of such tools by both providers and patients. Compounding this issue is the large number of tools resulting from 'homegrown' or academic pilot projects that do not meet market-level quality. To increase quality, more should be done to connect the needs of patients and providers to the entrepreneurial community.

Cultural competency is necessary but not sufficient

eHealth tools created by persons who do not represent the communities they want to reach may reflect mistaken assumptions about those communities. On the other hand, high-quality, easy-to-use technology may in some cases transcend the need for culturally specific tools (e.g. Facebook).

Elements needed to promote the development and adoption of eHealth tools aimed at reducing disparities, as ranked in the pre-meeting survey.

Future eHealth Equity Agenda

Whether elderly, minority, deaf, or blind, when removing barriers to access, education, and analysis, we find that the underserved are not as compartmentalized or isolated as we thought. There can be commonality between non-English speakers, deaf persons and elderly persons, when we focus on solutions as opposed to barriers.

Summit Participant

The summit concluded with a two-part discussion outlining priority agenda items for promoting and achieving eHealth equity, and documenting specific commitments towards those ends made by participants. Attendees were re-convened via webinar for a deeper discussion into priority areas. The sections below summarize some of the highlights from these exchanges.

Technology Agenda

- Continue drive to "liberate" health data, with the goals of increasing patient access and encouraging market-based innovation.
- Where needed, seek culturally appropriate technology solutions.
- Continue support for programs like the app challenges issued by ONC and OMH.
- Spur development of applications addressing empowerment needs that may not be met at the provider level, such as chronic disease self-management, caregivers, survivorship, and other self-help tools.

Participant Commitments
Several participants committed to taking steps to increase the availability of health data to patients through numerous electronic formats and by multiple means, including Blue Button. Participants also committed to efforts to expand information-sharing among healthcare organizations and other stakeholders. OMH restated its commitment to the app challenge concept, noting the recent Reducing Cancer Among Women of Color app challenge.

Education and Outreach Agenda

- Provide more education and outreach at several levels: among providers, within healthcare organizations, among patient populations, and broadly within underserved communities.
- Get equity issues on the health IT agenda through outreach at events like Datapalooza, HIMSS, Health 2.0, and HHS-sponsored 'code-a-thons'; increase participation in these events by representatives from underserved communities.
- Get health IT issues on the policy agenda of organizations providing leadership on other equity issues, including faith-based organizations.

Participant Commitments
Participants committed to meet these needs along several dimensions, with many highlighting programs to introduce or expand the use of eHealth patient navigators to provide culturally appropriate support to patients. Others pledged to expand outreach efforts within their own organizations and to reach out to other local community-based organizations through events and other venues. A group of participants agreed to increase their efforts around awareness of eHealth equity through their own blogs and other social media, and to coordinate those efforts. OMH noted its efforts to connect community-based advocacy groups to education and training tools at healthcare.gov and marketplace.cms.gov.

Research and Academic Agenda

- Support more research to build the evidence base for the positive impact of eHealth on health outcomes.
- Support more research about the impact of eHealth on providers and the clinical environment.

Participant Commitments
Some participants committed to conducting more of this research within their own organizations, particularly in ways that allow them to build on early successes demonstrated through pilot programs. Another participant added their intent to work on building eHealth and related equity issues into medical school curricula, to better prepare the next generation of professionals to deal with these issues.

Policy Agenda

- Leverage existing policies such as the Medicare and Medicaid EHR Incentive Programs to develop outcomes-focused goals for minority and other underserved populations.
- Explore ways to more fully integrate health equity issues with other major policy initiatives such as practice transformation, medical home models, and Healthcare Effectiveness Data and Information Set (HEDIS) quality measures.

Participant Commitments
Representatives from ONC committed to work collaboratively with stakeholders to explore ways that Stage 3 Meaningful Use requirements could address health IT disparities. In addition, ONC committed to share the findings from the Summit with the Consumer Empowerment Workgroup, part of the Health IT Policy Committee, to explore the need for health IT policy recommendations that facilitate advancement in these areas.

Next Steps for eHealth Equity

ONC's commitment is to be true to its own values, which start with open and inclusive processes, to reach out to the broadest group of stakeholders, to actively listen, and to keep our eyes on the prize, which is improved health and health care for all.

Dr. Farzad Mostashari
National Coordinator, Office of the National Coordinator for Health IT
U.S. Department of Health and Human Services

This summit represented neither the beginning nor the end of the conversation on eHealth equity. Rather, it was an opportunity to bring key stakeholders together to share their successes, their challenges, and their passion around these issues. Participants pledged not only to take lessons learned back to their own organizations, but also to continue the conversation by continuing to meet, and to find new ways to work collaboratively to make eHealth equity a reality.

ONC, OMH, and ZeroDivide would like to thank the planing workgroup for organizing the meeting, and the participants at the Summit for their contributions.

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