

April 3, 2020

The Office of the National Coordinator for Health Information Technology  
Office of the Secretary  
United States Department of Health and Human Services  
[healthit.gov](http://healthit.gov)

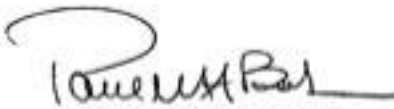
re: Request for Comments on draft 2020-2025 Federal Health IT Strategic Plan

Office of the National Coordinator for Health Information Technology:

Enclosed in reference to the above document are the comments of the Georgia Institute of Technology (Georgia Tech), Center for Advanced Communications Policy (CACP).

Should you have any questions concerning this filing, please do not hesitate to contact me via email at: [paul.baker@gatech.edu](mailto:paul.baker@gatech.edu).

Respectfully submitted,



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Attachment

**The Office of the National Coordinator for Health Information Technology  
Office of the Secretary  
United States Department of Health and Human Services  
Washington, D.C. 20201**

The U.S. Department of Health and Human Services (HHS) released the draft 2020-2025 Federal Health IT Strategic Plan, January 15, 2020, for public comment. The draft plan outlines federal health information technology (health IT) goals and objectives to ensure that individuals have access to their electronic health information to help enable them to manage their health and shop for care. The strategic plan was developed by the HHS Office for the National Coordinator for Health Information Technology (ONC) in collaboration with more than 25 federal organizations.

**COMMENTS OF  
GEORGIA INSTITUTE OF TECHNOLOGY (GEORGIA TECH), CENTER FOR ADVANCED COMMUNICATIONS  
POLICY (CACP)**

Georgia Tech's Center for Advanced Communications Policy (CACP) hereby submits comments in the above-referenced request for comments released on January 15, 2020. CACP is recognized at the state and national level as a neutral authority that monitors and assesses technical developments, identifies future options, and provides insights into related legislative and regulatory issues. The Center for Advanced Communications Policy (CACP) further focuses on key issues that influence the development, implementation and adoption of cutting-edge, advanced communications technologies. CACP work includes assessment of policy issues and production of regulatory filings, identification of future options for innovation, and articulation of a clearer vision of the ever-changing technology landscape. Center research areas include wireless communications and platforms; accessible technology design and use for people with disabilities; emergency alerts and communications; higher education policy and evaluation; workforce development and employment for people with disabilities; new communications modes such as social media and online participatory platforms; STEM (science, technology, engineering, and mathematics) education, and the cultural impact of technology shifts.

We believe it is essential that information and communications technologies (ICT) and services increase their levels of accessibility for people with disabilities; as access to technology can enhance inclusive and independent living. Since 2001, CACP has been actively involved with research

and regulatory issues concerning accessible ICT and wireless communications and devices. The comments respectfully submitted below are based on subject matter expertise developed over the past years. Findings from our research inform the observations made herein.

### **Page 8: Challenges in Healthcare**

*[...] "Additionally, expanded reliance on health IT can potentially exacerbate health disparities at the individual and population levels due to unequal access to and use of technology among certain populations. For example, while personalized health information apps may help smartphone users manage their health, people without access to smartphones will not experience this benefit. In contrast to these challenges, the use of health IT also provides opportunities to address or mitigate some challenges, especially those related to poor health outcomes and access to care. For example, telehealth capabilities could bring new services to rural populations with a shortage of healthcare providers."*

Healthcare delivery has been significantly impacted by the growth of the Information Society, fueled by a multiplicity of elements that generate pervasive and radical economic, social and technological changes. Planning for effective and equitable Health IT requires leveraging of Information and Communication Technologies (ICTs) in a manner which is especially sensitive to vulnerable and underserved populations, as is noted in the draft strategic plan. We feel it would be helpful if the plan recognized in addition to the noted rural and aging populations, the need for inclusion of people with disabilities (PWD) which has been recognized as an urgent priority worldwide.<sup>1</sup>

The challenges of designing inclusive policy goes beyond the stated need for access, which can be challenging in terms of simple connectivity to digital services, as well as due to economic barriers, to include issues of accessibility and usability. The technology and services must be accessible and usable to the end-user, as well as have usability -- in this case, the information must be provided in a way which has meaning (hence, usable) to critical stakeholders.

<sup>1</sup> UNESCO, "WSIS [World Summit on the Information Society] Forum 2015: Making Empowerment a Reality - Accessibility for All," [ [http://www.unesco.org/new/en/media-services/single-view/news/wsis\\_forum\\_2015\\_making\\_empowerment\\_a\\_reality\\_accessibilit/](http://www.unesco.org/new/en/media-services/single-view/news/wsis_forum_2015_making_empowerment_a_reality_accessibilit/)].

## Page 9: Challenges in Healthcare: Access to Technology

*[...] Minority, low income, tribal, and rural populations are less likely to have broadband internet service at home than others. Lack of access to broadband-dependent technology and health information made available through technology can further exacerbate existing health disparities by creating a barrier to the range of technologies that support cost-effective and high-quality care.*

We strongly agree that these are critical objectives, and wish to note again, that while access to broadband connectivity is lacking in a number of geographical contexts, or for which economic barriers can impede achieving the promises of Health IT, that the factor of *accessibility* be included in policy planning. For people with disabilities, access to Health IT, and associated services is dependent not only on a reliable connection to broadband but also the ability to use digital services in a manner that is accessible to them. As with the general U.S. population, people with disabilities have become significant users of the Internet<sup>2</sup> and wireless technologies, and hence by extension need to have representation in strategic Health IT planning.

ICT access has social, cultural, and political opportunities for users, enabling for social inclusion and access to community, educational, commercial, professional, and governmental resources.<sup>3</sup> Further, access to these resources for people with disabilities is dependent on *accessibility*, both the accessibility of the devices needed to access the internet, as noted in the draft strategic plan, and of accessibility of the *content* and *information* component of Health IT. “For a technology to be accessible, it needs to be usable in an equal or equitable manner by all users without relying on specific senses or abilities, and it needs to be compatible with assistive technologies that users may rely on [...] and many other devices that persons with disabilities may employ.”<sup>4</sup> Thus, we urge that the goals and objectives of the final 2020-2025 Federal Health IT Strategic Plan specifically take into consideration these accessibility concerns.

*Even when patients and caregivers can access health information electronically, they may have low levels of health literacy and may not understand what the information means. This is a significant challenge for improving patient health, especially as individuals are increasingly being expected to take a greater role in managing their own health and care...*

<sup>2</sup> Pew Research Center (2010). Americans living with disability and their technology profile.

[<http://www.pewinternet.org/2011/01/21/americans-living-with-disability-and-their-technology-profile/>]

<sup>3</sup> Jaeger, P. (2006). “Assessing Section 508 compliance on federal e-government Web sites: A multi-method, user-centered evaluation of accessibility for persons with disabilities.” *Government Information Quarterly* 23: 169-190.

<sup>4</sup> Jaeger, P. [2002]. *Disability and the Internet: Confronting a Digital Divide*. Boulder, Colorado: Lynn Rienner Publishers.

In addition to the issue of *accessibility*, design and implementation of Health IT needs to take into consider issues of *usability* – which can help ameliorate issues low levels of literacy, or comprehension of complex systems and technologies. One of the greatest barriers to adoption of new technologies is lack of usability.<sup>5</sup> While usability testing is fairly well established in consumer product development<sup>6</sup>, the impact of complex Health IT systems do not always consider the (end) user and hence the information presented by services and systems may be robust, yet not totally understood by patients, and in some cases, caregivers. Broadly, policy approaches and system testing focused on typical adults needs to be expanded to those with accessibility needs, as technology that is untested across a wide range of demographic and other underserved groups may be too complex for some, hindering usability that could have been developed during the design process with proper inclusive design processes.<sup>7</sup> Effective and affordable adoption of Health IT technologies places all stakeholders in a better position to benefit from newer technologies.

### **Page 13: Goal 1: Promote Health and Wellness**

#### **Objective 1a: Improve individual access to health information**

*A key aspect of person-centered care is empowering individuals by providing them access to their health information. It allows patients to become more engaged in their care and management of their conditions and alleviates strain on caregivers who manage the care of their loved ones. To expand access to health information, it is necessary to improve access to technology, especially for populations in rural areas, persons with disabilities, racial and ethnic minorities, and those with low socioeconomic status.*

While the strategies do mention improve access to technologies: *“Improve access to smartphones and other technologies needed to attain and use health information, especially for at-risk, minority, rural, disabled, and tribal populations.”* We believe it would be advantageous if the strategies where expanded to specifically address the need to improve accessibility of health data and

<sup>5</sup> Denker, A.H. and Baker, P.M.A. (2020). Digital Tech for Inclusive Aging: Usability, Design and Policy. *Journal on Technology and Persons with Disabilities*, Volume 7, 2020.

<sup>6</sup> Moon, N.W., Baker, P.M.A., Goughnour, K.P. (2019). Designing wearable technologies for users with disabilities: Accessibility, usability, and connectivity factors. *Journal of Rehabilitation and Assistive Technologies Engineering*, 6, 2055668319862137.

<sup>7</sup> Baker, P.M.A.; Gandy, M. & Zeagler, C. (2015). Innovation and Wearable Computing: A Proposed Framework for Collaborative Policy Design. *IEEE Internet Computing*, 19(5),18-25.

information beyond access in a sense of connectivity. This typically is in a sense of people with disabilities, but also would benefit people with limited educational background as well as those for whom language comprehension represents a challenge to navigation of healthcare settings.

**Page 14 Objective 1c: Integrate health and human services information**

*Integrated health and human services data are necessary for providing person-centered healthcare and human services, and for understanding and addressing social determinants of health at the individual and population levels. Today, there is little integration of data between the various federal, state, territorial, regional and local agencies, and tribes, some of which provide care to the same beneficiaries. Additionally, there is almost no coordination between agencies in real-time, creating inefficiencies and inhibiting initiatives to address social determinants of health. Furthermore, community-based organizations providing health and human services (e.g., the aging and disability network funded by the Administration for Community Living) lack the requisite health IT infrastructure and adoption support that is needed in order to become fully integrated as a part of the care continuum.*

And

**Page 18 Objective 3b: Support research and analysis using health IT and data at the individual and population levels**

*Vast amounts of health data are generated every day at the individual and population levels that can be ethically leveraged for disease prevention, quality improvement, and outcomes research. The volume of data is growing at an astounding rate. Partners should continue to work together to support research and innovation advances.*

**Strategies**

- **Build the evidence base on use of health IT for improving quality through research that investigates the impact of health technologies on patient care, safety, and outcomes.**

We feel that these objectives are extremely important, and actually interlinked. Poor or miscommunication across organizational and institutional boundaries represents a key barrier to development of effective Health IT. We recommend adding a bullet point (under Objective 1c) that recognizes the need to address the issues that arise at the intersection of policy domains, for example the development of technology and societal equities, and those arising from problems that cross disciplinary and organizational barriers. Proactively exploring evidence-based research with stakeholder groups – public sector, developers, caregivers and patients, and developing implementation policy

focused on information translation, awareness building, and interagency-coordination will yield systems that better serve patients and caregivers, as well as other members of the healthcare ecosystem. This could also be stressed in an expanded manner under Objective 3B.

## **Page 15 Goal 2: Enhance the Delivery and Experience of Care**

### **Objective 2a: Ensure safe and high-quality care through the use of health IT**

*Healthcare providers can develop care plans and deliver high quality, safe, person-centered care when health systems and programs deploy tools that collect, store, and use health data that addresses the unique needs of each individual patient. Achieving this objective will require the application of technologies such as machine learning, improved patient matching, patient safety solutions, and mechanisms for data governance and provenance. It will also require providing care daily and in the event of a public health emergency or disaster.*

While mentioned in passing in the draft plan, emergency communications and disaster management are highly dependent on an effective, robust and resilient information infrastructure. Health IT systems are complex and their continued operation in uncertain or perturbed conditions needs to be thoughtfully planned for to avoid disruption to healthcare.

Modern emergency communications systems are composed of a number of technologies including legacy analog, digital technology and computer mediated networks. Individuals with disabilities can be a vulnerable population during emergency situations for several reasons. This diverse demographic represents those with sensory, cognitive, physical, perceptual, and those who are elderly or aging into disabilities. For those with a disability, it can be very important to clarify messaging, acquire more information, and ask questions to those that can help them best. Inclusive design of Health IT can serve both to coordinate information flow across hybrid and legacy systems (helping to cross legacy system and geographic boundaries). In a connectivity and information distribution mode, Health IT systems can additionally provide a framework to communicate, alert and support patients and caregivers by providing information at the point that is readily accessible (for instance via wearable devices), and facilitate connection with bottom-up social networks.<sup>8,9</sup>

<sup>8</sup> Bricout, J.C., & Baker, P.M.A. (2010). Leveraging online social networks for people with disabilities in emergency communications and recovery. *International Journal of Emergency Management*, 7(1), pp. 59-74.

<sup>9</sup> H. Mitchell, D. Bennett, and S. LaForce, (2011) "Planning for Accessible Emergency Communications: Mobile Technology and Social Media," 2nd International AEGIS Conference Proceedings, Brussels.

Although Federal agencies such as the Federal Communications Commission and DHS IPAWS are striving to ensure all emergency notifications are accessible, there still remains among other providers inconsistencies which often results in insufficient emergency communication information to people with disabilities. This is why we urge that the final 2020-2025 Federal Health IT Strategic Plan additional take into account the importance of the impact of emergency and disaster occurrences on Health IT systems. The current Covid-19 pandemic illustrates the importance of anticipating the disruptive effect of external conditions on Health IT systems. Further, sometimes because of the processes used to manage healthcare systems, people with disabilities are excluded and hence refer to their personal “trust” network.<sup>10</sup> Policy interventions that encourage the proactive inclusion of people with disabilities and their trusted networks in the planning stages of newer Health IT integrations could provide an important link to engagement, inclusion and usability of Health IT.

In closing, we commend the scope of ONC’s draft 2020-2025 Federal Health IT Strategic Plan, and offer the suggestions above to help increase the inclusivity and accessibility of Health IT. Further, as new Federal U.S. and global regulations and industry standards are negotiated, healthcare and telemedical access via mobile devices, cost effective delivery of broadband services to people with disabilities, especially all people living in rural areas, adaptive Health IT may well become a critical platform for service delivery among people with and without disabilities.<sup>11</sup> It is extremely important that 1) proactive Federal policy be developed and 2) regulatory bodies provide broad-based accessibility provisions that can deliver a flexible applicable architecture as Health IT evolves, with the ability to guide industry and engage appropriate stakeholders in developing accessible products and services that also promote usability of the same. As the ONC develops final 2020-2025 Federal Health IT Strategic Plan, we urge that these issues of accessibility and hence inclusivity of Health IT be a key objective.

The importance of IoT accessibility along many dimensions – technology, service, design, information access, and economics – was summed up in a recent article. While the article addressed, specifically, IoT, the insights are applicable to the development of effective, inclusive Health IT systems: “While the Internet of Things offers great benefits to all, people with disabilities stand to benefit

<sup>10</sup> M.P. Mackrell, K.J. Twilley, W.P. Kirk, L.Q. Lu, J.L. Underhill, and L.E. Barnes. “Discovering Anomalous Patterns in Network Traffic Data during Crisis Events.” Proceedings of the 2013 IEEE Systems and Information Engineering Design Symposium, University of Virginia, Charlottesville, VA. April 26, 2013.

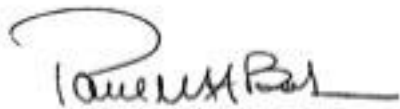
<sup>11</sup> Gould, M. & Studer, E. (2010). *Convention on the Rights of Persons with Disabilities (CRPD) 2010 ICT Accessibility Progress Report*. G3ict – the Global Initiative for Inclusive Information and Communication Technologies, 2010 [http://g3ict.org/resource\\_center/CRPD\\_Progress\\_Report\\_On\\_ICT\\_Accessibility\\_2010](http://g3ict.org/resource_center/CRPD_Progress_Report_On_ICT_Accessibility_2010)



considerably from connected technologies. The technology used to build smarter cities and smarter homes can help create a more accessible environment for people with disabilities and offer them the opportunity to live more independently.”<sup>12</sup>

To this end, the CACP wishes to emphasize the importance of including accessibility for people with disabilities to the greatest extent possible as part of the design and development of Health IT and associated services and policy.<sup>13</sup> To achieve these objectives, we urge that people with disabilities be consulted 1) throughout the design, development, and testing phases of Health IT systems, and (b) the accessibility implications of future technologies should become a high-level consideration when planning Federal level technology development strategies and policy.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Paul M.A. Baker". The signature is written in a cursive style with a large initial "P" and "B".

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Dated this 3<sup>rd</sup> day of April 2020

<sup>12</sup> J. New, “The Internet of Things Means a More Accessible World”, <http://www.datainnovation.org/2015/05/the-internet-of-things-means-a-more-accessible-world/> [retrieved: May 2015]

<sup>13</sup> Baker, P.M.A.; Gandy, M. & Zeagler, C. (2015). Innovation and Wearable Computing: A Proposed Framework for Collaborative Policy Design. *IEEE Internet Computing*, 19(5) (September-October).