Spotlight

Shaping the Future of Digital Health

Key Themes Emerging from a Series of Roundtables on the Health Data Revolution

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Technology is transforming nearly every aspect of the consumer health care experience, with applications that generate, capture, and leverage consumer health data rapidly proliferating. Federal policy makers, meanwhile, are exploring how to facilitate the capture, sharing, and use of data across the health care ecosystem. Appropriately, they are also considering the right policy responses concerning the broader implications and unintended consequences of this transformation, such as those related to protecting privacy and ensuring security in information sharing.

To explore the impact of this ongoing digital health revolution on consumers and help shape the development of policy and practice in this issue area, in summer 2019 the AARP Public Policy Institute (PPI) joined the National Partnership for Women & Families to host a three-part series of PPI's Innovation Roundtables, which are off-the-record conversations intended to foster open dialogue. The "Shaping the Future of Digital Health" Innovation Roundtable series brought together advocates for consumers, family caregivers, and groups that focused on broader consumer and health information issues to discuss the future of health and health care—and the role consumers can play in shaping that future—as all aspects of individuals' lives become increasingly digitized and connected.

Without attributing comments to any stakeholder, what follows is a look at each of the three Innovation Roundtables and the salient themes that emerged from them.

Roundtable 1
Imagining the Future: How Technology Will Revolutionize Health

The first meeting in the "Shaping the Future of Digital Health" series took on the challenge of imagining ways technology and data use could positively shape consumers' health care experiences. It explored the external forces

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influencing the future of health. What emerged was a combination of opportunities and issues about which stakeholders should be mindful. Issues and themes included the following:

Health and Technology Literacy. Roundtable participants surfaced the potential reality that a connected health care system will increase the importance of technology literacy among consumers, while also compounding the already-existing need to improve health literacy. In addition to understanding how to use digital platforms, people will need to understand the uses, benefits, and risks of emerging health technologies. Participants observed that it will be important to effectively identify and engage individuals with the most to gain from digital health technologies (e.g., lower-income individuals and others with less social capital).

Collaborative Design. Roundtable participants noted that, rather than technology developers building a product and then bringing in consumers for testing, end-users should be involved from the start, driving critical research and development to ensure technology prioritizes their values. For example, digital platforms must be usable and accessible for all individuals, including non–English speakers, people with disabilities, and members of low-income groups without technology access, among others. Particular attention should be paid to:

- *Curating Connection and Emotional Intelligence.* Social media and electronic communication platforms can foster connections between individuals—but can also breed division and amplify tension. Developers should consider whether and how their technological concept or prototype could be used to foster connection and empathy rather than enhance social isolation.

- *Costs and Access.* The cost of new technologies, and Internet access itself, can be a significant barrier to access the technology; exacerbating disparities. Affordability remains a top concern for health care consumers. Roundtable participants said that new technologies must be accessible and beneficial for low-income populations. At the same time, if resources are limited, they should be deployed strategically so that health care providers

and communities have the resources they need for essential health care services as they invest in new technologies.

Agency in a Surveillance Culture. Remote monitoring technologies have shown promise in allowing care recipients, many of whom live alone or often are left unattended, to be monitored for safety purposes. Yet, while remote monitoring technologies can provide a sense of safety and security for health care recipients and their caregivers alike, some participants worried that they can also contribute to anxiety and cognitive stress often found in those under a high level of surveillance. Consumers, therefore, must be empowered to make dynamic and granular choices about how and when they interact with such technology. Technology that confers agency to people should be a priority.

Addressing and Eliminating Bias. In order to realize the promise of digital technology to improve health, participants raised the point that health systems first must acknowledge and dismantle already-existing structural racism and other forms of discrimination embedded in policies and practices that have deleterious effects on certain communities or perpetuate inequities. Policy makers should enforce and, as is necessary and appropriate, develop additional consumer protections and antidiscrimination policies to address existing and prevent new avenues of bias. Examples of practices that must be prevented include data being used as the basis to deny or delay coverage, increase rates, or otherwise limit consumers' access to care.

Roundtable 2
Navigating the Future: Promises and Pitfalls of Emerging Health Technologies

The second meeting focused on exploring the risks and unintended consequences of emerging technologies that generate, capture, and leverage consumer health data. In addition to cataloging the challenges related to digital health technologies, participants discussed shared values that can serve as guideposts when assessing policy and practice.

As part of this dialogue, participants examined the issue of fairness in precision medicine—that is, the

emerging field of tailoring treatment and prevention to individuals based on variables ranging from their genes to their lifestyle and environment. For example, studies have documented the shortcomings of artificial intelligence (AI) at its current level of maturity. AI, we now increasingly understand, is only as good as the data on which it is based. If marginalized groups do not trust data collection or use, they will not participate in the health care system and therefore may not be represented in data sets that inform precision medicine—thereby potentially exacerbating existing disparities in health outcomes. Moreover, Roundtable participants underscored that policy and regulation should ensure that predictions about current and future health status derived from precision medicine applications are not used to discriminate against certain populations.

Discussion also centered on current legislative efforts related to data sharing, both in the United States and abroad. Surfacing as an overarching value was the importance of social connection—between individuals, their families, and their health care providers, including those providers' team members. Person-centered technology should enhance the health care experience, making it easier and more convenient for people.

Also echoing a broader technology debate was an in-depth discussion on the idea of granting consumers certain indelible data rights—protections that cannot be waived. Currently, consumers are often given a false choice: if they agree to a company's terms of service, their data can be amassed, used, and sold. If consumers do not agree, they are denied the opportunity to use the service or platform.

Roundtable 3
Shaping the Future: Putting Consumers at the Heart of Digital Health

This final roundtable centered on transparency and portability. Issues and themes included the following:

Consumer Trust and Education. A lack of consumer trust might undermine *all* data sharing, as Roundtable participants discussed. In the wake of highly publicized breaches like the Cambridge

Analytica data scandal, consumers might become overcautious about sharing their health information, and be unwilling to share even clinical information already protected by such laws as the Health Insurance Portability and Accountability Act (HIPAA) or the Genetic Information Nondiscrimination Act. Without a strengthening of trust moving forward, tension will exist between the desire to enable the flow of health information for beneficial purposes and the individual's need for privacy.

Health Data Commodification. Today's commodification and monetizing of data affects every single part of the American economy. Online platforms' primary source of revenue often is the consumer data they collect rather than the products they sell. Consumers who do not realize how their information is being used—and sold—cannot meaningfully consent given the opaque and lengthy terms and conditions of most apps and digital services. Given the personal nature of the data involved, the implications are particularly significant in health care.

Consumer-Mediated Exchange. Despite the lack of transparency and risks associated with health data sharing, there is interest in consumer-mediated exchanges, in which consumers can easily access, compile, and manage their own digital health information. However, Roundtable participants surfaced an important issue on this topic: consumers generally do not understand when their health information leaves a HIPAA-protected environment, or the ramifications of how these data may be sold or used to discriminate against them, or the burden that may be imposed on them to shuttle their health information from one provider to another.

Roundtable Wrap-Up: Options

Finally, at this final Roundtable in the series, participants together developed a list of policy options to explore:

- Require plain-language disclosures mandating that companies disclose their terms of service in *accessible* language that makes it easier for consumers to understand how their data may be used.

- Support revocable consent, affording consumers the right to have personal data erased from databases and terminate the future use and sale of data. Revocable consent would allow consumers to tailor their data-sharing preferences to evolving privacy priorities and/or phases of health.

- Establish a consumer-controlled identity credential that would facilitate a nonprofit clearinghouse or health information exchange allowing free flow of health data (including for commercial purposes). This approach would address the issue of consumers having to create and maintain multiple identification credentials with potentially different terms of service as well as allow providers to outsource certain security functions, such as authentication. The approach also could enhance fraud detection.

- Launch a public education campaign to inform individuals and providers about consumer rights and responsibilities regarding health data, as well as the implications of data sharing (e.g., how information seemingly unrelated to health could be used to make inferences about people's current and future health status).

- Create personalized "My Terms of Service," a set of terms and conditions related to data sharing and use tailored to reflect individuals' preferences that companies must accept (created by a third party). Consumers then have control over permissions and authorizations to access their data.

- Issue an annual consumer report on personal health data, similar to existing annual credit reports. The health data report would include information on which entities are accessing the data, what fields are being collected, details about an error-correction process, and how to revoke consent.

Looking Ahead: Getting the Right People at the Table

The Roundtable series revealed that advocates for consumers and family caregivers see the potential for health data and emerging technologies to transform the care experience. However, they also see cause for concern—specifically regarding the potential for health data to be used to discriminate against individuals through such practices as denying them services or imposing additional burdens.

Guarding against such outcomes will require input from all stakeholders who will be impacted by their use. As technology developers continue to innovate and policy makers consider how to update laws and policy, the voices, perspectives, and priorities of consumers must be central to the equation. Without this input, the resulting policies and practices may exacerbate harms or discriminatory uses—especially for individuals with lower incomes, communities of color, immigrants, people with disabilities, and other groups with limited networks and resources.

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