The ubiquity and use of smartphones, sensors, devices, and wearables that monitor, diagnose, and improve health behaviors is exploding. We track our health habits by strapping wearables to our wrists, attaching patches to our skin, and even ingesting sensing pills that transmit signals to our health care providers (Topol, Steinhubl, & Torkamani, 2015). Deluges of data are analyzed for insights at lightning speed.

These personalized health technologies (PHTs) produce completely new categories of data that make precision medicine both a reality and potentially cost-effective. The voluminous data trails these smartphones, sensors, devices, and wearables leave behind also open new doors for misuse and harm by well-intentioned innovators and malevolent characters. Innovation of PHT is several laps ahead of ethical, legal, and social (ELS) considerations that are needed to allay legitimate concerns of prospective users and their health care providers. Is this personal health data accurate, reliable, and trustworthy? Is it wise to share publically on social networks or privately with health care providers? Are companies reusing the data for marketing or advertising purposes? Is it protected from cybercriminals? Uncertainty in these areas may limit the quality, acceptability, uptake, and potentially revolutionary benefits of PHT. Collective action by varied stakeholders is needed to eliminate ELS barriers of PHT use for individual and societal benefit.

Ethical, Legal, and Social Implications of Personalized Health Technology

Innovations from scientific discoveries may not be publically accepted because of ethical or legal concerns, or because of their failure to meet societal needs. For example, discrepancies in the global uptake of genetically modified foods persist, primarily due to insufficient investment throughout their development in understanding what is required for society to consider them to be safe. On the other hand, the Human Genome Project’s proactive approach to addressing ELS implications led to broad acceptance of genetic and genomic research. President Obama’s Precision Medicine Initiative may not lead to public benefit unless it explores pressing ELS implications.

Technological advances with ethical dimensions necessitate robust science. Weak or insufficient evidence can fuel judgments based on ideology, or subjective perceptions of benefit or risk. The relative newness of PHT reflects an evidence base in its infancy with modest research demonstrating its effectiveness. Studies on how to improve health-related behaviors with these technologies are increasingly including proven principles of behavioral economics or behavior change techniques (Michie et al., 2013; Volpp, Asch, Galvin, & Loewenstein, 2011). Nonetheless, much more evidence about the use of PHT to promote behavior change must be generated, synthesized, and presented in ways that enable decision-makers to understand its value.

Legal concerns may also hinder progress in PHT. The President’s Council of Advisors on Science and Technology (2014) concluded: “Only in some fantasy world do users actually read [privacy] notices and understand their implications before clicking to indicate their consent.” Insufficient attention to how privacy is protected or how personal health data from PHTs is used may result in unanticipated or irrevocable consequences for companies and consumers. Concerns exist about whether personal health data is being...
used by companies in ways that consumers do not expect, including sharing information with undisclosed third parties or with entities in countries that might have different rules with respect to data privacy and use. Designing PHTs with privacy considerations “baked in” through approaches like “privacy by design” may help mitigate if not avoid these legal issues (Cavoukian & Jonas, 2012).

Social concerns may further impede the uptake of PHTs and their potential health gains. Different groups profit unequally from innovation. At present, many PHTs benefit the younger and affluent “worried well” rather than high-risk and marginalized populations; digital divides continue to widen as new and often expensive PHTs enter the marketplace. Poor health literacy and numeracy further inhibit interpretation and use of PHT data to support informed health decision-making. These issues must be taken into account in the design of PHTs if they are to have widespread impact on individual and public health.

ELS challenges are often perceived as impediments to progress, but this need not be the case. A responsible approach to innovation engages society in considerations of the ELS implications of technology through the entire development process. Responsible innovation anticipates and evaluates the potential implications and societal expectations of technology in ways that are democratic, equitable, and sustainable (European Commission, 2013).

Consultation for Collective Action: Guidelines for Personalized Health Technology

To advance consideration of ELS implications of PHT, we hereby launch a global public consultation on a draft set of Guidelines for Personalized Health Technology (Vitality Institute, 2015). The guidelines include six recommendations: (1) Ensure PHTs use principles of evidence-based approaches to health behavior improvement, such as behavior change techniques and behavioral economics; (2) Design PHTs with the aim of promoting utility and equitable accessibility across diverse populations; (3) Integrate approaches like privacy by design in the development and management of PHTs and supporting systems; (4) Advance user-centered design of PHTs; (5) Enable evidence on PHTs demonstrating validity, reliability, and other key performance metrics; and (6) Facilitate transparency with respect to data stewardship.

These guidelines are intended to serve as a set of principles for the responsible development of PHTs and stewardship of their associated data. Their impact demands input from the full range of stakeholders in PHT: health care professionals, payers, academic researchers, public policymakers, designers and developers of PHT, and concerned consumers. The Vitality Institute, an action-oriented and evidence-based health promotion and chronic disease prevention research organization, will pilot these guidelines with these stakeholders. The uptake and utility of these guidelines will be assessed using independent evaluators. Based upon this evaluation, the guidelines will be revised and promoted as a self-regulatory framework for the PHT industry that can help assure that PHTs have a sustained positive impact on the health of the public.

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