



# GUIDELINES FOR PERSONALIZED HEALTH TECHNOLOGY: FINAL REPORT

March 2016

Vitality™

## Authors

Gillian P. Christie, MPhil, MA, The Vitality Group, New York, USA

Kevin Patrick, MD, MS, Center for Wireless and Population Health Systems, The Qualcomm Institute, University of California, San Diego, California, USA

Derek Yach, MBChB, MPH, The Vitality Group, New York, USA

## The Vitality Group

The Vitality Group is a member of Discovery Ltd., a global financial services organization offering an incentive-based health and well-being program to employers as part of their benefits program. With a foundation based on actuarial science and behavioral economic theory, Vitality encourages changes in lifestyle that reduce health care costs, both in the short run and long term, by rewarding members for addressing their specific health issues. Vitality well-being programs serve companies in a wide range of sizes and industries, improving individuals' health and well-being as well as employers' bottom lines.

For more information, visit [www.vitalitysmarterchoices.com](http://www.vitalitysmarterchoices.com).

## The Vitality Institute

The Vitality Institute is an evidence-driven, action-oriented research organization dedicated to building a culture of well-being by promoting health and preventing chronic diseases. The Institute aims to unite leaders in the public and private sectors to transform evidence into action and build a culture of health. The Institute was founded in 2013 by the South African insurer, Discovery Ltd., as part of its commitment to health promotion and well-being programs that advance social good.

For more information, visit [www.thevitalityinstitute.org/elsi](http://www.thevitalityinstitute.org/elsi).

Contents

Executive Summary..... 1

Introduction..... 3

Guidelines for Personalized Health Technology..... 7

Conclusion: A Call to Action..... 27

Appendix: Scorecard..... 29

References..... 32

Acknowledgments..... 33



GUIDELINES

# Executive Summary



Health innovation is undergoing a radical transformation worldwide. It is becoming personal, predictive, and preventive. Rooted in this evolving reality are personalized health technologies – devices such as wearables from Fitbit, smartwatches from Apple, and mobile health applications from Under Armour – that passively quantify our health behaviors when strapped to our wrists or placed in our pockets. Sophisticated sensors monitor our heart rates, accelerators count our steps and note our sleep patterns, and global positioning services detect our locations. Deluges of data are analyzed at lightning speed for actionable insights.

An era of consumerism that engages and empowers consumers in their own health decisions is having profound implications for the prevention and management of complex and costly diseases. Personalized health technologies that enable consumers to track their health remotely can support physicians in delivering precision medicine and academics in uncovering variations in health behaviors among disparate populations. The rapid innovation of these devices and use of associated data have generated concerns on their development and deployment. Deal-breaking questions – Will my employer be able to access and analyze my data? Will my insurer use my data to price my premium? Will my data be protected and secured from malevolent cybercriminals? – may result in a failure to deliver widespread health benefits if they remain unanswered.

## Guidelines for Personalized Health Technology

We propose a set of guidelines to develop a self-regulatory approach for the personalized health technology industry. These guidelines are intended to overcome emerging concerns by providing a blueprint for the responsible innovation of these devices. Best practices identified from a public consultation hosted between July and October 2015 serve to inform the guidelines.

### Guidelines for Personalized Health Technology

1. Build health technologies informed by science.
2. Scale affordable health technologies.
3. Guide interpretation of health data.
4. Protect and secure health data.
5. Govern the responsible use of health technology and data.

## A Call to Action

We call for the public and private sectors to join in partnership to pilot, implement, and report on the proposed guidelines for personalized health technology. The guidelines would be measured independently using tangible metrics, and results would be shared publicly in corporate reports. Collaborating across the public and private sectors, our proposed guidelines seek to shift the dialogue around personalized health technologies to promote shared values for all stakeholders.



GUIDELINES

# Introduction



## Introduction

Space explorations, nuclear threats, the Vietnam War, and civil rights movements: that was the 1960s. Scientific upheavals and societal shifts stimulated intellectual debates and controversial countercultures throughout the decade. When smoking was rampant, epidemiologic inquiries into the harms of smoking were released in the United Kingdom (1962) and the United States (1964).<sup>1,2</sup> After minicomputers were invented in 1960, Gordon E. Moore was ahead of his time (1965) in proposing the doubling of transistors in an integrated circuit every 2 years.<sup>3,4</sup> Since then, Moore's Law has remained indisputable. John Lennon said, in a 1980 interview, "The thing the sixties did was show us the possibility and the responsibility that we all had. It wasn't the answer. It just gave us a glimpse of the possibility."<sup>5</sup>

Today, discoveries from the '60s have blended to create innovations with impact. Epidemiology and computer science have collided to develop a fast-growing ecosystem of personalized health technologies – devices such as wearables from Fitbit, smartwatches from Apple, and mobile health applications from Under Armour. When strapped to our wrists or placed in our pockets, these devices passively measure our health behaviors. Sensors monitor our heart rates, accelerators count our steps and note our sleep patterns, and global positioning services (commonly referred to as GPS) detect our locations.

The possibilities for better health using personalized health technologies appear endless. Consumers can quantify their health remotely to motivate behavior changes, physicians can deliver precision medicine to their patients, and academics can expose variations in health behaviors among diverse populations. The Wild West of innovation in this industry has sparked concerns regarding the development and deployment of these devices. Governments with opportunities to promote innovation often mandate approvals that lead to companies' simplifying personalized health technologies to avoid regulatory requirements. Without clearly defined rules or detailed regulations enforced by governments, pressing queries arise quickly: Will my employer be able to access and analyze my data? Will my insurer use my data to price my premium? Will my data be protected and secured from malevolent cybercriminals? Any potential opportunities to use data and technology to improve individual or societal health may fail to materialize without convincing answers to these deal-breaking questions.

“ Legitimate fears about data security, and perceived lack of privacy of personal health data, could become a barrier to accessing quality healthcare. ”

– Mark Creager, President,  
American Heart Association

Twenty-five years ago, the Human Genome Project was founded as an international research collaboration to sequence human genes.<sup>6</sup> The collection of sensitive genetic information spurred the early allocation of public funds to foster basic and applied research on related ethical, legal, and social implications. This research served to guide policy options regarding the appropriate use of genetic information. Today, established and accepted protocols facilitate the routine sharing of genetic data for research.

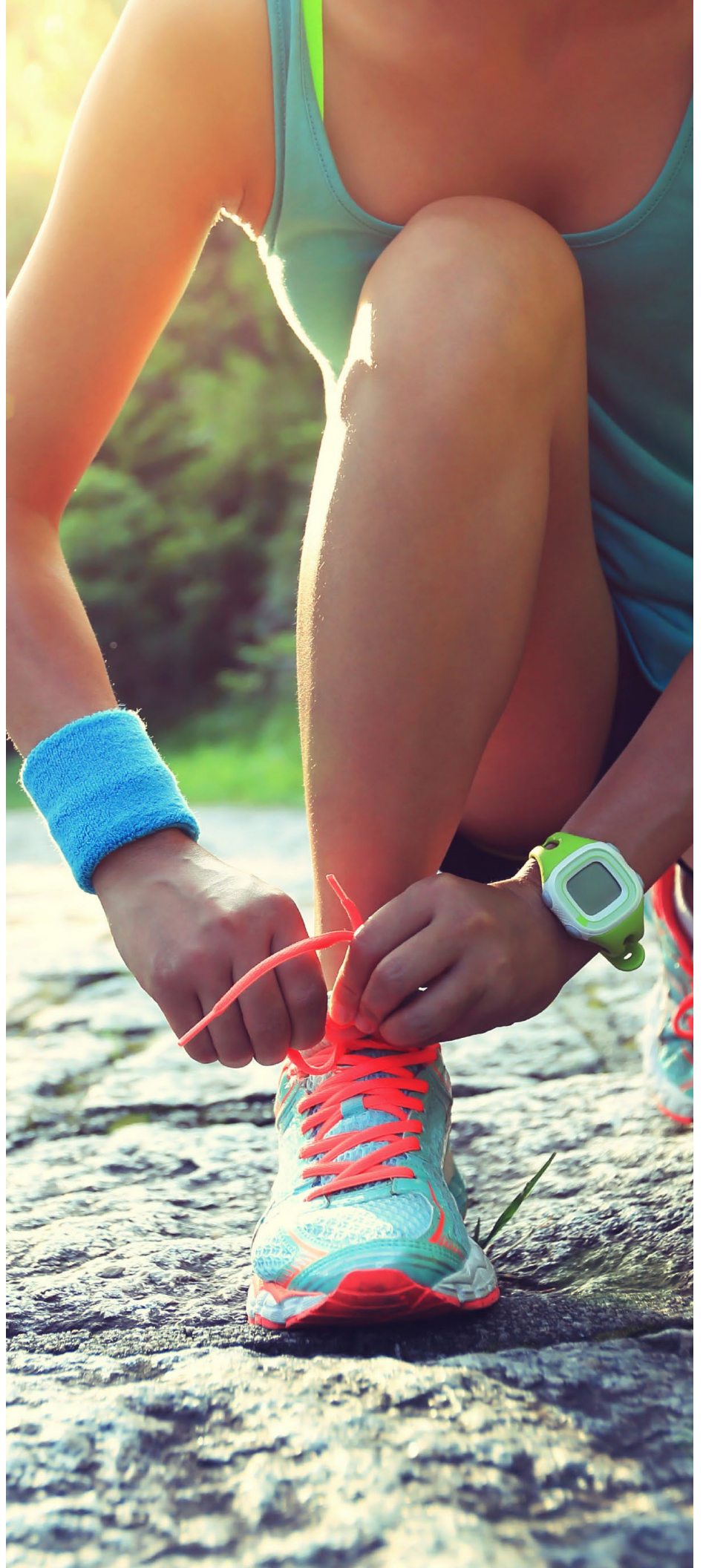
The vision for these guidelines is informed by past achievements in proactive exploration of ethical, legal, and social concerns with the possession of genetic information. We seek to create a self-regulatory approach for the responsible innovation of personalized health technologies. A set of guidelines would focus on the development of these technologies and the deployment of their associated data. Resulting from collaboration across the public and private sectors, these guidelines are intended to shift the dialogue around personalized health technologies to promote shared values among stakeholders. They represent our approach to addressing the challenges ahead. A scorecard is included in the Appendix as a strategy to operationalize the guidelines.

The guidelines are ambitious and aspirational but attainable through influential leadership and cooperation among diverse stakeholders. Each guideline includes suggestions of best practices that can inform a blueprint for the responsible innovation of personalized health technologies. The strategies are derived from a public consultation on an earlier version of the guidelines hosted between July and October 2015.<sup>7</sup> Quotes included in this report are taken from feedback received during the public consultation.

### Public Consultation on Guidelines for Personalized Health Technology

In July 2015, an open-access, peer-reviewed commentary published by colleagues at Vitality, Microsoft, and The Qualcomm Institute at the University of California, San Diego called for a public consultation to identify best practices to eliminate ethical, legal, and social barriers to personalized health technologies.<sup>8</sup> For 90 days between July and October 2015, a wide range of stakeholders offered input on a draft set of guidelines. Feedback came from organizations such as the European Union Commission, the US Food and Drug Administration, the National Academy of Medicine, and the American Heart Association. Later in October, feedback received during the consultation was shared on a webinar.







GUIDELINE

# 01

Build health  
technologies  
informed by science



## Build health technologies informed by science

Japanese walking groups using early pedometers advocated taking 10,000 steps each day.<sup>9</sup> Today, 10,000 is often considered the magic number of daily steps every person should take to improve his or her health – to reduce body mass index, boost mental well-being, and minimize the risk of type II diabetes and heart disease. Time after time, taking 10,000 steps each day has been proven to be an effective metric for leading a longer and healthier life.<sup>10</sup> Despite the benefits to health of such interventions, companies designing personalized health technologies often unsystematically – or entirely neglect to – integrate scientific or behavioral evidence into their devices. A majority also do not test the impact of their interventions on improving health.

Personalized health technologies designed with scientific and behavioral evidence and tested with robust research methods can promote a transparent marketplace. Consumers can determine the potential of a device to help them manage their health, companies can market their devices based on real data, and clinicians can prescribe devices to their patients knowing they will be reimbursed. Overly stringent or heavy-handed requirements for testing prior to market launch could impede innovation. There may be multiple ways to know whether a new technology that incorporates longstanding evidence and has undergone rigorous study will be equally or more effective than other untested approaches. Developers of personalized health technologies require flexibility to establish what works to change health behaviors, and they need time to test and refine their products.



It is **absolutely critical** that health technology is  
based on **sound evidence**.



– Michael Sagner, President,  
European Society of Lifestyle Medicine,  
Paris, France



“Optimal design is a moving target.”

– Deborah Estrin, Professor of Computer Science,  
Cornell Tech, NY, USA

Personalized health technologies that are informed by evidence seek a balance between function and form. Scientific and behavioral evidence are incorporated into the design of the technology, and innovation in user experience is fostered through iterative experimentation and adaptation. Interventions that are known to improve health are balanced with designs that have the potential to be effective as well as widely adopted and used. These technologies can be evaluated through research approaches such as observational studies or A/B testing that quickly assess their acceptability and effectiveness using data generated by consumers. User feedback builds evidence to determine the impact of various designs on health based on rapid iterations of the technology.

### What Is A/B Testing?

A/B testing is used routinely by technology developers for rapid assessment of the impact of product-design modifications on user behavior. A/B testing refers to a randomized experiment with two variants. Variant A could be users who have downloaded a mobile health application in its existing format, Variant B could be users who have downloaded a modified version of the mobile health application. The impact of the change in design on behaviors in Variants A and B are compared over time to maximize the outcome of interest – namely health.

## Best Practices

- Partnerships between technology developers and health/medical researchers exist to support evidence generation and inclusion. Evidence on effective and ineffective interventions is shared with users and across disciplines and industries.
- Scientific and behavioral evidence is graded based on its robustness and the extent to which it is integrated into personalized health technologies. Evidence is generated when lacking or unavailable.
- Feedback mechanisms are integrated into the design of personalized health technology to support the trial, error, and iterative improvement of the technology. These include rapid enhancements based on user data to quickly determine a technology's ease of use, utility, and cost.



Build in the ability to **adequately assess** the efficacy of the resource [technology] **based on user data.**

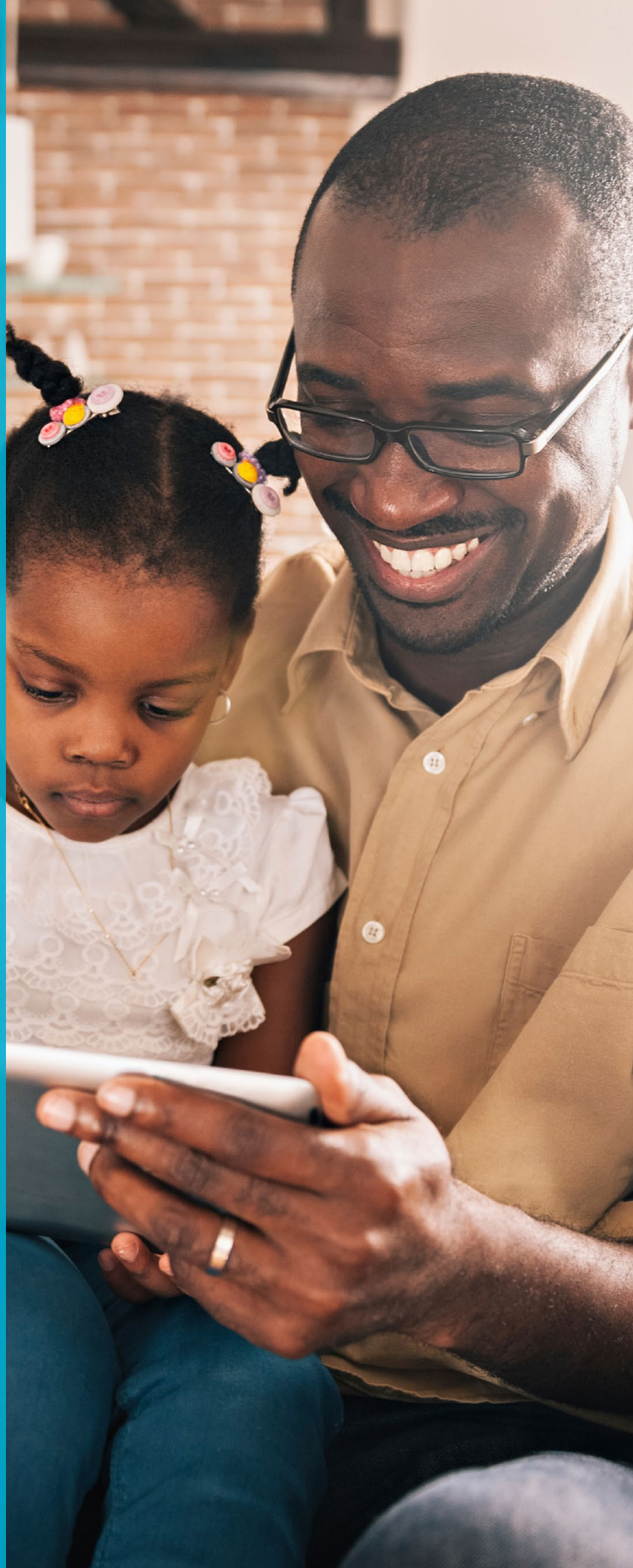


– Erik Augustson, Behavioral Scientist,  
National Cancer Institute, Washington, DC, USA

GUIDELINE

# 02

Scale affordable  
health technologies






## Scale affordable health technologies

Current incentives to create innovative technologies often lead companies to recoup their initial investments in research and development through high prices for early adopters. Prices decline over time as processes become more efficient and competitors enter the market with rival products. As a result, early adopters of personalized health technologies are commonly individuals with discretionary incomes. High prices render the technology unaffordable for low- and middle-income populations. Even though mobile phone penetration now stands at 96% globally, marginalized populations continue to have unequal access to the platforms that support advanced personalized health technologies.<sup>11</sup>

Individuals with low incomes also often have poor health, a pattern that holds true for vulnerable populations worldwide. Those who could benefit the most from using personalized health technologies are financially constrained and lack access to the technology. Because of patterns and practices of employment, these individuals may also be unlikely to receive personalized health technologies through their employers or insurers. The result may be that personalized health technologies contribute to the widening, and not the narrowing, of digital divides in health.



Healthcare improvement and innovation efforts must be efficient, scalable, equitable, and transparent. 

– Andrey Ostrovsky, Co-Founder,  
Care at Hand, MA, USA

Innovative models founded on collaborative partnerships are needed to ensure that personalized health technologies benefit all populations. Public-private partnerships are one model that leverage resources from the public and private sectors to solve critical development challenges. They may include innovative financing models such as social impact bonds or pay-for-performance arrangements to measure outcomes. Unique partner and financing combinations can support broader access to technologies for those who are unable to afford them. When new personalized health technology is under development, a frugal innovation mindset to design devices with and for low-income communities may result in an appropriate price point from the outset. Technology can leapfrog ahead to support its own affordability and accessibility.

### Learning From Experience: Pharmaceuticals

Pharmaceuticals for a variety of debilitating illnesses often exist but are unavailable to all but a few individuals. In many African countries where HIV/AIDS is prevalent, the cost of life-saving antiretroviral drugs is about \$12,000 per year – a price out of reach for everyone but a handful of people.<sup>12</sup> The development of generic drugs by pharmaceutical companies and their subsidization by state and nonstate actors have reduced the cost of antiretroviral drugs. A similar public-private partnership model with innovative financing could be applied routinely to personalized health technologies to make them accessible to more than simply a few.

### Best Practices

- Partnerships between the public and private sector can support broader access to and affordability of personalized health technologies.
- Innovative financing models are used that enable win-win situations for disparate stakeholders, including individuals, companies, and governments.
- Future users of personalized health technologies are engaged throughout the development and testing process to facilitate inclusive designs.





GUIDELINE

# 03

Guide interpretation  
of health data



## Guide interpretation of health data

Apple's mobile health application, HealthKit, encourages users to log their nutrition on a daily basis. It recommends logging foods with biotin, folate, and iodine and enquires about intake of magnesium and manganese. A majority of individuals would not know which foods contain these nutrients, let alone the appropriate levels of daily consumption. Individuals who are health literate have the capacity to interpret basic health information and make informed decisions about promoting and maintaining their health. Unfortunately, the World Health Organization estimates that nearly half of all Europeans have inadequate or problematic health literacy, and in the United States as many as 9 out of 10 adults lack the skills needed to manage their health.<sup>13,14</sup>

Poor health literacy and numeracy contribute to poor health. This is because the relationships between risk factors that underpin a healthy life (like eating wisely and exercising regularly) and various health outcomes may not be understood. The inability for users of personalized health technologies to interpret their health data sufficiently contributes to poor health outcomes. If users are unable to initiate changes in their behaviors based on data, their engagement with the technology is likely to decline. Currently, a mismatch exists between those consuming health information and those designing the technologies that deliver this information.

“ The people who can benefit the most ... often have troubles with the usability and utility of many personalized health technologies. ”

– Ryan Shaw, Assistant Professor,  
Duke University, NC, USA

Customizing the experience of personalized health technologies to a user's level of health literacy can improve engagement. Cultural and linguistic preferences, along with simple descriptions and visualizations of data, can guide users in the interpretation of their health information. Facilitating better consumption of health data may also entail testing the technology with users of different ages, cognitive abilities, and socioeconomic status to determine appropriate design features for engagement. Inclusion of end users in the design and testing of personalized health technologies to meet them at an appropriate point in their health journey can overcome challenges of poor health literacy. Tailoring personalized health technologies to the individual user will require systems of artificial intelligence, including machine learning and predictive analytics, to analyze and deliver data in a way that nudges the healthy choice to become the easy choice. Blizzards of data will need to be analyzed in real time and translated into understandable and actionable information.

## Best Practices

- Personalized health technologies are designed and tested for heterogeneity and adaptation.
- End users with diverse backgrounds, including linguistic, cultural, and health literacy differences, are engaged in the technology design and testing processes.
- Data are presented with appropriate considerations for health literacy, including communication and visualization of the information.





## Tracker

Today's performance

### AVERAGE SPEED



### DISTANCE





GUIDELINE

# 04

Protect and secure  
health data



## Protect and secure health data

Since 2009, the health information of more than 120 million people in the United States has been compromised by an estimated 1,100 data breaches.<sup>15</sup> Sophisticated hackers can allegedly attack Fitbit devices within 10 seconds via Bluetooth technology.<sup>16</sup> Despite the rising occurrence of health data falling prey to high-profile cyberattacks, the mechanisms used by corporate entities to protect and secure health information have become ever more opaque to consumers. Individuals frequently consent to privacy policies without ever fully understanding the approaches used by companies to protect or secure their health data.

Information asymmetry between companies and consumers is increasing. Scrutiny by regulators and consumers regarding companies' unclear data activities can yield unexpected surprises. Any corporate handling of health data that is misaligned with user expectations – such as the selling or renting of data – quickly discourages trust. Sustained engagement with personalized health technologies to maximize health or minimize costs is unlikely to be realized for communities worldwide without rigorous data privacy and security practices.

“ Privacy-by-design and integrated security mechanisms are the way to go. ”

– Bartha Knoppers,  
Director of the Centre of Genomics and Policy,  
McGill University, Quebec, Canada

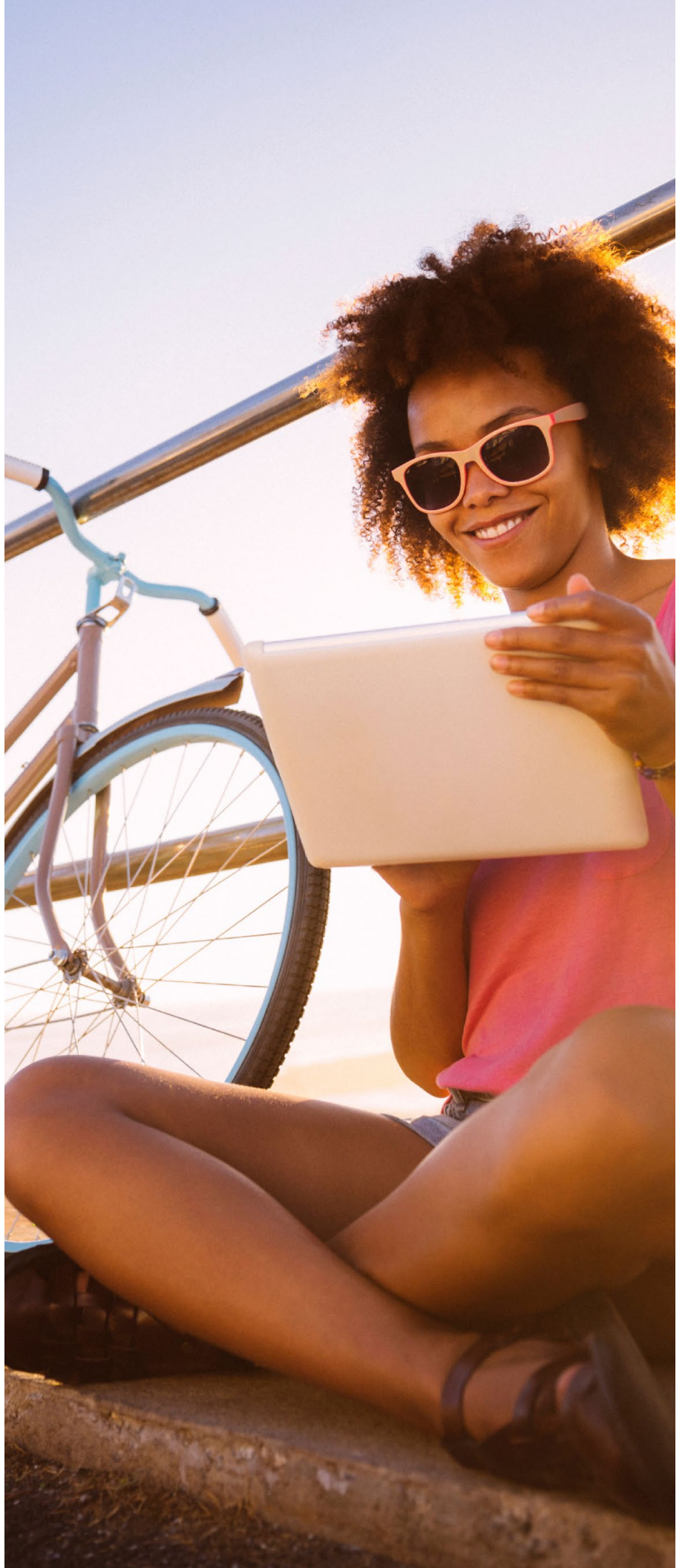


Although regulations have historically been the preferred action to protect health data, businesses have broadly accepted that legislation cannot ensure the future of privacy or security. Although corporate leaders across industries express concern about their ability to protect sensitive data, winning the trust of consumers remains instrumental to business growth and brand reputation.<sup>17</sup> Among a majority of companies, privacy by design and security by design have emerged as boardroom matters. Privacy by design embeds privacy features into new technologies and supporting business practices from the outset and throughout the development process. It adopts a preventive approach to ensure cradle-to-grave and end-to-end support of privacy.<sup>18</sup> In the European Union, privacy by design will be mandatory when the General Data Protection Regulation is adopted.

Strong privacy must be accompanied by strong security. Security by design integrates security components into new technologies and systems from the earliest stages of conception and design. For personalized health technologies, privacy and security need to be integrated into the design and objectives – and may ultimately prove to be a differentiator for success.

## Best Practices

- Privacy and security features are integrated into technology design from the outset. Privacy policies are short and simple and offer consent on meaningful options. State-of-the-art security incorporates secure transactions and storage of data by integrating encryption and deidentification as default settings. Third parties with access to data are named, and data are not sold under any circumstances.
- Product designers, as well as consultants such as professional hackers, are empowered to anticipate and respond to user concerns throughout the process of designing technology to uncover and eliminate vulnerabilities.
- Corporate decisions on privacy and security value the interests of stakeholders over commercial goals. Codification and audit of privacy and security protocols using objectives measures are shared by company leaders. Reporting on data practices is treated in the same way as financial and physical assets. Companies are transparent in disclosing how data from personalized health technologies are used.



GUIDELINE

# 05

Govern the  
responsible use of  
health technology  
and data





## Govern the responsible use of health technology and data

In 1970, the Nobel prizewinning economist Milton Friedman proposed that the social responsibility of business was to maximize shareholder value.<sup>19</sup> Companies had one objective: to increase profits. The historical focus of placing profits before people has often led to corporate activities that jeopardize potential benefits to society and the environment. In these situations, companies are thought to be prospering at the expense of communities. The increasing ability of technology to dodge regulations and to manipulate public perceptions has contributed further to the demise of society's trust of business. This also erodes consumers' trust while impacting a company's revenue and reputation.

Optimizing short-term financial performance often leads to a shortage of transparency and accountability in corporate practices. A lens of maximizing shorter-term profitability over longer objectives could deceive the public regarding how personalized health technologies are developed and deployed. Consumers may be blindsided when data are used inappropriately or in ways that are misaligned with their expectations. The worst case is for users simply to be too hesitant to engage with the technology at all, with few if any benefits to health being realized.



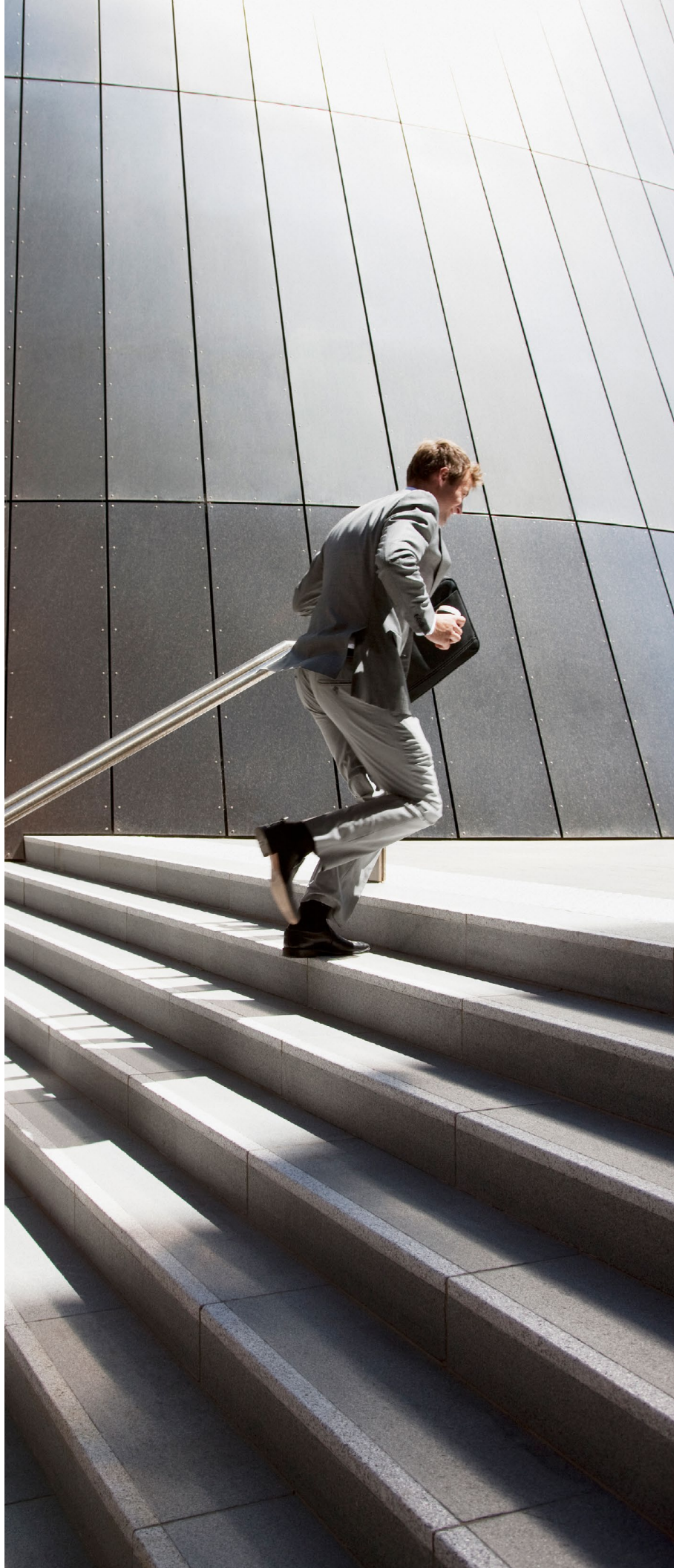
Markets can incentivize irresponsible behaviors. Companies need to build their trustworthiness to gain our trust. ”

– Hilary Sutcliffe, Director, MATTER –  
Making New Technologies Work For Us All  
England, United Kingdom

Since being introduced by Milton Friedman, models of shared value have been proposed by Michael Porter and Mark Kramer to redefine the purpose of business.<sup>20</sup> Shared value implies that companies and society can generate economic value in ways that also create value for society. Corporate success and social progress are intertwined. Transparency and accountability of corporate practices associated with personalized health technologies can foster shared value between companies and society. Building trust by disclosing data practices and technology design can benefit the bottom line and the health of societies. Corporate governance to support principles of responsible innovation that are continuously assessed and refined, as opposed to quarterly reporting on gains and losses, can build public trust. This requires adopting a long-term lens on research and development, transparency and accountability, and business and societal impacts.

## Best Practices

- Corporate boards and senior management publicly embrace and articulate the values of responsibly innovating for corporate and societal benefit.
- Strategies for profit maximization are balanced with initiatives that will improve the health of societies over the long term.
- Companies partner with independent third-party auditors to develop practices and protocols on the responsible use of personalized health technology using tangible and standardized metrics.





GUIDELINES

# Conclusion:

## A Call to Action



## Conclusion: A Call to Action

Knowledge about drivers of health and well-being – including the human body, environmental influences, and social networks – is undergoing rapid transformation. Personalized health technologies that generate flows of actionable data are facilitating better prevention and management of complex and costly diseases. Galvanizing transformations to health that are sustained and widespread, however, may not materialize unless concerns regarding the responsible development and deployment of these devices are proactively mitigated. Waiting any longer for others to take action will only impede innovation and progress.

Our guidelines for personalized health technology propose a blueprint for change. Simply stated, personalized health technologies should be informed by science and behavioral evidence, and should be affordable and accessible to all populations. Data generated by these technologies should be easily interpretable, protected and secure, and available in a transparent and accountable marketplace. These guidelines have the potential to lead to an optimal future for the use of personalized health technologies.

Global collaboration by disparate stakeholders is essential for the broad dissemination and implementation of the guidelines. We call for organizations representing the private and public sectors to work in partnership to measure fulfillment of the guidelines independently using tangible metrics, with results shared publicly in corporate reports. Committing to transparency and accountability engages, empowers, and encourages stakeholders to go above and beyond baseline legal requirements and create shared value for global communities.

We can promote change today, or we can deal with unintended consequences tomorrow. Better health will not be realized, for this or future generations, through irresponsible innovation or mismanagement of personalized health technologies and their associated data. As John Lennon reminds us, possibilities for good exist; navigating the responsibilities will only serve to democratize health in a digital world.

“ **Anyone** should be able to operate health technology safely with sufficient awareness of protecting privacy, and correctly, in order to prevent incorrect information being provided to a healthcare provider or system. ”

– Tom Glynn, Consulting Professor,  
Stanford University, CA, USA

GUIDELINES

# Appendix





## Scorecard

A preliminary scorecard, comprising 42 questions, has been developed that incorporates concrete metrics to be used as a management tool by organizations interested in piloting and implementing the guidelines. The scorecard is an instrument for managers to determine the extent to which their organization addresses ethical, legal, and social considerations of personalized health technologies and data stewardship.

The scorecard is intended to be completed by legal, compliance or product leads engaged in designing and deploying personalized health technologies or facilitating data practices and protocols.

Following completion, a score for each section is generated by awarding 1 point per category. The objective is for companies to have a zero score in the “Never” category and a majority of points in the “Often” column (i.e. it is not about an overall “score” or ranking). Companies with responses in the “Never” category should work toward shifting them toward the “Often” category.

It is suggested that companies use the scorecard at least once a year, or more frequently if relevant. They will not be required to publicly disclose responses to the questionnaire. Feedback on the scorecard can be provided to Gillian Christie at [gchristie@thevitalitygroup.com](mailto:gchristie@thevitalitygroup.com).

GUIDELINE 1: Build health technologies informed by science	NEVER	SOMETIMES	OFTEN
Does scientific evidence inform the design of health technologies?			
Does behavioral evidence inform the design of health technologies?			
Are feedback mechanisms integrated into the design of health technologies?			
Is evidence generated to determine the effectiveness of health technologies?			
Are rapid testing methods (such as A/B testing) used to determine the effectiveness of health technologies?			
Are users of health technologies notified that their data may be used to generate evidence?			
Is evidence on effective and ineffective interventions using the technology shared with users?			
Is evidence on effective and ineffective interventions shared across disciplines and industries?			
Do academic partnerships guide the design of health technologies?			
GUIDELINE 2: Scale affordable health technologies	NEVER	SOMETIMES	OFTEN
Are health technologies affordable for all populations?			
Are health technologies accessible to all populations?			
Do collaborations between the public and private sectors support the affordability of health technologies?			
Do collaborations between the public and private sectors support access to health technologies?			
Are innovative financing mechanisms used to support broader access to health technologies?			
Are the affordability views of users considered in designing health technologies?			
GUIDELINE 3: Guide interpretation of health data	NEVER	SOMETIMES	OFTEN
Are gender preferences integrated into the design of health technologies?			
Are ethnic preferences integrated into the design of health technologies?			
Are linguistic differences integrated into the design of health technologies?			
Are data from health technologies presented clearly and visually to users?			
Are descriptions to facilitate interpretation of data included in the design of health technologies?			
Are disparate users of health technologies engaged in the entire development process?			
Are health technologies designed to nudge individuals to improve their health?			
Are systems of artificial intelligence used to tailor health technologies to users' needs?			
GUIDELINE 4: Protect and secure health data	NEVER	SOMETIMES	OFTEN
Are principles of privacy by design integrated into health technologies?			
Do users provide consent to share their data from health technologies?			
Are privacy notices communicated to users when policies change?			
Can users modify their privacy settings to determine which data are shared with third parties?			
Are users' data communicated to third parties in an aggregated format?			
Are third-party vendors' privacy practices evaluated when partnerships are being considered?			
Can users restrict data collection to functions required for health technologies to operate?			
Is the sale of users' data from health technologies prohibited?			
Is the use of users' data for marketing or advertising purposes prohibited?			
Is the sharing of data restricted across country borders?			
Are principles of security by design integrated into health technologies?			
Are users' data from health technologies anonymized?			
Are users' data from health technologies encrypted?			
Are users' data from health technologies destroyed upon termination of use?			
GUIDELINE 5: Govern the responsible use of health technology and data	NEVER	SOMETIMES	OFTEN
Do corporate boards articulate values of responsible innovation of health technologies?			
Does senior management articulate values of responsible innovation of health technologies?			
Do values of profit maximization balance with initiatives that improve health and societies?			
Does an independent organization evaluate health technology and data practices annually?			
Are results from external evaluations of health technology and data practices made publicly available?			
SCORE			

## References

1. Royal College of Physicians, Smoking and health. 1962. Available at <https://www.rcplondon.ac.uk/projects/outputs/smoking-and-health-1962>. Accessed January 21, 2016.
2. United States Office of the Surgeon General, Smoking and Health. 1964. Available at <http://profiles.nlm.nih.gov/ps/access/NNBBMQ.pdf>. Accessed January 21, 2016.
3. Davis RM. Evolution of computers and computing. *Science*. 1977;195(4283):1096-1102.
4. Moore GE. Cramming more components onto integrated circuits. *Proceedings of the IEEE*, 1998;86(1):82-85.
5. Wiener J. Lennon's Last Interview: 'The Sixties Showed Us the Possibility'. *The Nation*. December 8, 2010. Available at <http://www.thenation.com/article/lennons-last-interview-sixties-showed-us-possibility/>. Accessed January 19, 2016.
6. National Human Genome Research Institute. An Overview of the Human Genome Project. 2015. Available at <https://www.genome.gov/12011238>. Accessed January 21, 2016.
7. The Vitality Institute. Personalized Health Technology. 2015. Available at <http://thevitalityinstitute.org/projects/personalized-health-technology/>. Accessed January 21, 2016.
8. Christie GP, Patrick K, Schmuland D. Consultation for collective action on personalized health technology: eliminating ethical, legal, and social barriers for individual and societal benefit. *J Health Commun*. 2015;20(8):867-868.
9. Tudor-Locke C, Bassett Jr DR. How many steps/day are enough? Preliminary pedometer indices for public health. *Sports Med*. 2004;34(1):1-8.
10. Choi BC, Pak AW, Choi JC, Choi EC. Daily step goal of 10,000 steps: a literature review. *Clin Invest Med*. 2007;30(3):E146-E151.
11. International Telecommunication Union, ICT Facts and Figures. 2013. Available at <http://www.itu.int/en/ITU-D/Statistics/Documents/facts/ICTFactsFigures2013-e.pdf>. Accessed January 21, 2016.
12. Chang H-J. *Bad Samaritans: The Myth of Free Trade and the Secret History of Capitalism*. New York, NY: Bloomsbury Publishing; 2008.
13. World Health Organization, Health Literacy. The Solid Facts. 2013. Available at [http://www.euro.who.int/\\_data/assets/pdf\\_file/0008/190655/e96854.pdf](http://www.euro.who.int/_data/assets/pdf_file/0008/190655/e96854.pdf). Accessed January 21, 2016.
14. U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion. Quick Guide to Health Literacy. Available at <http://health.gov/communication/literacy/quickguide/factsbasic.htm>. Accessed January 21, 2016.
15. Peterson A. 2015 is already the year of the health-care hack — and it's only going to get worse. 2015. *The Washington Post*. Available at <https://www.washingtonpost.com/news/the-switch/wp/2015/03/20/2015-is-already-the-year-of-the-health-care-hack-and-its-only-going-to-get-worse/>. Accessed January 21, 2016.
16. Murgia M. Fitbit can allegedly be hacked in 10 seconds. 2015. *The Telegraph*. Available at <http://www.telegraph.co.uk/technology/internet-security/11947164/Fitbit-can-allegedly-be-hacked-in-10-seconds.html>. Accessed January 21, 2016.
17. PricewaterhouseCoopers, 10 Minutes on data privacy. 2014. Available at <http://www.pwc.com/us/en/10minutes/assets/pwc-data-privacy.pdf>. Accessed January 21, 2016.
18. Information and Privacy Commissioner of Ontario. Privacy by Design. Available at <https://privacybydesign.ca/>. Accessed January 21, 2016.
19. Friedman MO. The Social Responsibility of Business is to Increase its Profits. *The New York Times*. September 13, 1970:SM17.
20. Porter ME, Kramer MR. Creating shared value. *Harvard Business Review*. January-February, 2011.



## Acknowledgments

Vitality thanks the following individuals and organizations for their contributions to this report:

Feinstein Kean Healthcare (Skye Schulte, Tom Langford, Shannon Miller)

Stef Stendardo, SCS, Inc

The Vitality Group (Shahnaz Radjy, Sarah Kunkle)

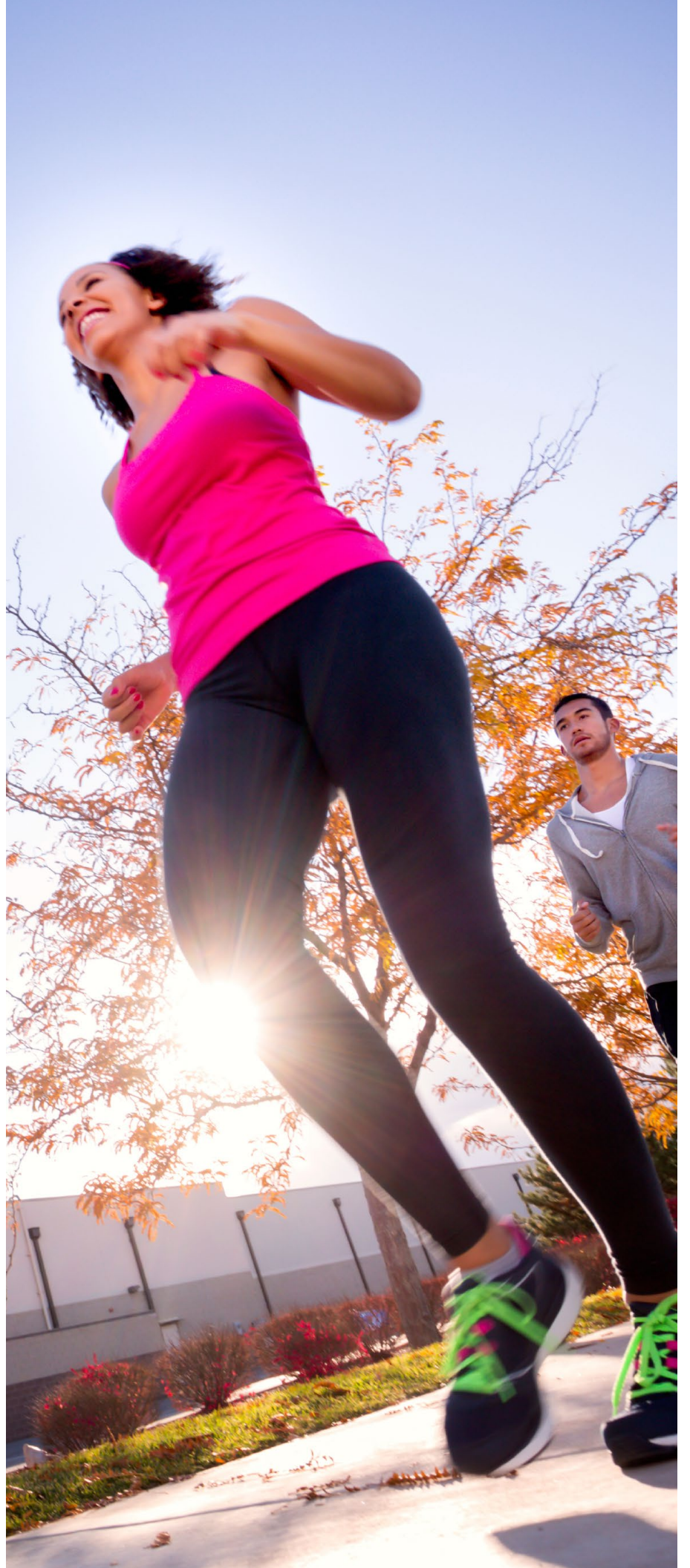
Vitality also extends thanks to the individuals and organizations who provided input through the public consultation:

American Heart Association; Anita Fineberg, Anita Fineberg & Associates Inc.; Andrey Ostrovsky, Care at Hand; Deborah Estrin, Cornell Tech; Howard Bolnick, Simon Hendrie, Gary Kantor, Discovery; Ryan Shaw, Duke University; Heather Patrick, Envolv PeopleCare; European Commission; Michael Sagner, European Society of Lifestyle Medicine; Skye Schulte, Feinstein Kean Healthcare; Jules Polonetsky, Future of Privacy Forum; Paul Edwards, Hannover Re; Luke Allen, Harvard University; Fikry Isaac, Johnson & Johnson; Michelle Davis, Health and Human Services; Connected Health Committee, HIMSS; Hilary Sutcliffe, MATTER; Bartha Knoppers, McGill University; Kathryn Coburn, Murphy Cooke Kobrick LLP; Erik Augustson, National Institutes of Health; Matt Balogh, Ogilvy CommonHealth Worldwide; Lochlan McHale, ProofPilot; Tom Glynn, Stanford University; Natasha Gajewski, Symple Health; Rhonda Cornum, TechWerks; Elle Alexander, Leonard Aucamp, Rob Benedict, Lauren Chana, Cothar Hajat, Sarah Kunkle, Nick Lucero, The Vitality Group; Ross Anderson, University of Cambridge; University of Edinburgh; and 11 anonymous contributors.

## Disclosures

The Vitality Group is a wholly owned subsidiary of the South African insurer, Discovery Ltd.

The mention of any individual or organization in this report does not mean that they endorse the guidelines or any other material included in this report.



Vitality™