Patient-generated health data: a pathway to enhanced long-term cancer survivorship

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ABSTRACT

The growing ability to collect and transmit patient-generated health data, also referred to as people-generated health data and patient-reported outcomes (PROs), are clinically relevant data captured outside of traditional care settings that can be used to improve outcomes and enhance patient-provider communication. These data originate from a variety of sources, including, but not limited to, PRO measures (PROMs), such as the Patient Reported Outcomes Measurement Information System (PROMIS); approved medical devices such as blood glucose monitors; remote sensors, such as motion detectors; consumer wearable devices such as fitness bands; and mobile phone applications (apps). Blood pressure readings taken at home, heart rate measurements taken during physical activity, movement monitoring via remote sensors in the home, sleep phase data recorded via a wearable device, and disease symptom ratings collected via survey instruments are some examples of PGHD. Although no specific set of PGHD to support general health maintenance or long-term management of chronic conditions has been defined, all existing sources of PGHD, and potentially others that are in development, could be incorporated into patient- and condition-specific approaches to managing patients’ health.

Systems that support PGHD allow individuals to collect personal health data based on what is meaningful to them for managing their health and to choose whether and with whom to share that data. When patients choose to create PGHD and providers agree to accept PGHD to address specific clinical aims, such as monitoring a patient’s sleep quality, PGHD may extend the patient-physician relationship by providing concrete observations of certain aspects of a patient’s health and helping patients identify medical needs that they can bring up during clinical encounters. PGHD also allow individuals to explore health-associated issues that are of interest to them, but which typically fall outside the clinical environment (such as adoption of dietary changes associated issues that are of interest to them, but which typically fall outside the clinical environment (such as adoption of dietary changes). PGHD to address specific clinical aims, such as monitoring a patient’s sleep quality, PGHD may extend the patient-physician relationship by providing concrete observations of certain aspects of a patient’s health and helping patients identify medical needs that they can bring up during clinical encounters. PGHD also allow individuals to explore health-associated issues that are of interest to them, but which typically fall outside the clinical environment (such as adoption of dietary changes and stress management techniques). As interest in patient engagement grows, providers are coming to recognize and value the personal health data that patients gather for their own use and share during clinical encounters. Although patient-generated information has historically been considered valid only when it is correlated with objective outcomes measures (eg, test results, mortality, and morbidity), there is growing recognition that patient-generated data are meaningful to the patient and can positively inform patient care, and thus need not be correlated with traditional outcomes.

This shift in thinking is particularly important in the context of cancer care, given that, although outcomes measures specific to cancer care are reported, quality-of-life measures that survivors value when making healthcare and life decisions are less often available. For example, a cancer survivor might wish to start an exercise program or start a job requiring a greater level of activity than he or she currently undertakes. Chronic progressive cardiomyopathy is a known late effect of the chemotherapy drug doxorubicin, and although laboratory-based exercise testing protocols can be used to estimate an individual’s exercise capacity, the results of such tests (eg, an exercise target in metabolic equivalents) may not be very meaningful to cancer survivors, particularly when they are taking up an increased level of activity after many years of sedentary life or for the first time. Using a wearable device that transmits PGHD, however, will allow cancer survivors to track changes in heart rate, blood pressure, time to muscle exhaustion, and other variables at different activity levels, so that the survivor and healthcare provider can make an informed decision together about whether the survivor can, for example, step up from 5K to 10K road races, train for an Olympic sprint triathlon, or go hiking with his or her grandchildren. Such information would also inform cancer survivors’ broader life decisions, such as what career(s) to pursue, which climate(s) will minimize future health problems, and whether to have children.

CANCER SURVIVORSHIP

Although cancer survivorship has been recognized as an issue of importance for several decades, variation in the disease course and treatment of different cancers as well as in patients’ personal circumstances results in a highly individualized cancer experience. This spectrum of experience is sufficiently broad to preclude a single definition of “survivorship.” Cancer survivorship can be characterized as a time frame (eg, 5 years post-treatment), an outcome (eg, remission), a stage (eg, after treatment), or as the process of living with cancer and its aftermath. From the perspective of patients, however, survivorship is an experiential phenomenon, and over time, survivorship may be viewed as survival through and beyond the period during which...
treatment side effects, late effects (treatment-related health problems occurring months or years after treatment), and prognosis can be projected. Over the years, certainty about the long-term effects of cancer treatment shrinks while the risks of treatment-related morbidity and early mortality grow, leaving cancer survivors with an increasing need to monitor and manage their health.

Although cancer was once regarded as a death sentence, survival rates have greatly improved during the past 4 decades. The 5-year relative survival rates for breast, skin melanoma, prostate, testicular, and thyroid cancers are at or above 90%, and survival rates for other common cancers also have increased. As of January 2014, there were almost 14.5 million child and adult cancer survivors in the United States, a number projected to increase to nearly 19 million by January 2024.

However, even when survivors recover their health, cancer treatment places them at higher risk for health problems and an early death. Late effects experienced by cancer survivors may include, but are not limited to, changes in cardiac, pulmonary, vascular, endocrine, metabolic, reproductive, and immune function. Survivors may experience ongoing fatigue, chronic pain, peripheral neuropathies that limit extremity function, temporary or permanent cognitive changes, and other problems. Surgery can leave cancer survivors with permanent disabilities or disfigurements, which may limit their independence. In addition, the cancer experience changes how survivors see themselves and relate to their families, friends, and coworkers. Chemotherapy, radiation therapy, and surgery remove the evidence of cancer, but also create new health challenges for survivors that require life-long care.

Some cancer survivors, typically those who have experienced relatively fewer late effects of treatment, remain active and use integrative medicine and complementary modalities to manage their health. Others rely on alcohol and tobacco products to cope and live sedentary lifestyles that are undesirable, given their risk of late effects impacting the heart, lungs, and metabolism. In addition, survivors often do not know what to do to preserve or improve their health post-treatment; fewer than half of the cancer survivors on Medicare reported receiving detailed information from their provider about follow-up care, and fewer than a quarter of cancer survivors 18–64 years old who have private insurance were told about the side effects of their therapies.13

Healthcare providers and cancer survivors have different expectations for survivorship care. In one study comparing survivors’ expectations to those of oncologists and primary care physicians (PCPs), survivors expected oncologists to be far more involved in survivorship care than oncologists thought they should be, and both oncologists and PCPs envisioned themselves as being highly involved in survivors’ cancer screening but not in other areas of survivorship care. In another study, PCPs reported a willingness to assume full responsibility for survivors’ follow-up care, though oncologists believe that they are more qualified to care for survivors than PCPs, and pediatric oncologists have reported varying levels of willingness and ability to follow long-term follow-up surveillance guidelines for cancer survivors. In another study, a majority of cancer survivors reported that their physicians failed to understand how cancer treatment affected their quality of life, did not adequately explain how to maintain their health, and did not understand them on a personal level. Even when survivors perceive that their PCPs provide high-quality care, they have expressed concerns about PCPs’ survivorship-related care.

PGHD’s ROLE IN CANCER SURVIVORSHIP CARE

The ability to gather and share relevant health data offers cancer survivors and their healthcare team the opportunity to improve survivors’ health while building stronger patient-physician relationships. Using PGHD is of particular benefit to cancer survivors, whose disease treatment and late effects vary significantly and who may require individualized follow-up care. The broad array of tools that generate PGHD supports a flexible, customized approach that facilitates patients’ and physicians’ investigation of those health aspects they deem to be important while minimizing the burden on survivors experiencing no cancer-related health concerns as well as providers with limited ability to monitor PGH and/or incorporate it into survivors’ care. PGHOs have been shown to be acceptable to cancer patients and physicians take more actions to address symptoms when they are in use, though the evidence of their impact on outcomes is mixed and implementation challenges remain. There has been less investigation into the value of PGHD created by other means, but the growing popularity of personal tracking devices and the ongoing development of environmental sensors suggest that such investigations are on the horizon. Thus, clinical and consumer informatics professionals who bring their expertise to bear on the challenges of implementing PGHD-based survivorship care models can make a lasting impact not only on providers’ ability to serve their patients, but also on cancer survivors’ health.

PGHD furthers cancer survivorship care across three domains: support of survivor autonomy, improvement of survivor health, and promotion of survivor population health.

Support of Survivor Autonomy

PGHD Facilitates a Survivor-Defined Life

PGHD makes a self-defined, rather than disease-defined, life possible. By analyzing PGHD, cancer survivors can identify patterns of late effect or health condition exacerbation, proactively adjust their schedule and care routines to minimize interruptions of their daily routine, and optimize their health status over extended periods of time.

PGHD Facilitates Measuring What Matters to Survivors

PGHD makes it possible to measure what researchers and clinicians think may help them manage cancer survivors’ care or what health product manufacturers want to report in marketing materials. Patient-generated PROMs allow survivors to measure what they believe will help them and their providers manage their care, based on their lived experience.

PGHD supports the use of health behavior change to improve health interest in addressing social and behavioral risk factors (eg, tobacco use, sedentary lifestyle) within healthcare settings has grown as the impact of these risk factors on individual and population health has become clearer. However, even if a standardized set of health behavior measures is integrated into electronic health records (EHRs), clinical workflows as well as patient needs and expectations may limit the meaningful use of such measures, at least initially. Collection and analysis of PGHD, whether in the form of established measures completed by patients or in non-standardized forms such as activity records, can advance the integration of health behavior change data into cancer survivors’ medical records.

Improvement of Survivor Health

PGHD Facilitates Coordination of Care

Long-term cancer survivors frequently develop relationships with multiple healthcare providers, some of whom (eg, acupuncturists) may not use electronic medical records or otherwise share patient data. Survivors thus must assume responsibility for collecting symptom and care data and maintaining personal health records that may exist outside the EHR(s) used by their providers. Transmission of PGHD to provider-managed EHRs allows providers to better understand survivors’ needs and coordinate care among multiple medical providers.
**PGHD Can Help Providers Identify Issues That Survivors May No Longer Recognize or Fail to Mention in Clinical Situations**

For example, an elderly prostate cancer survivor may not leave the house because he has urinary incontinence after undergoing prostate surgery. With PGHD detailing the survivor’s activity habits, his doctor can initiate a conversation in which the survivor acknowledges that surgery-related complications make him fearful of leaving home, and the physician can arrange for patient education, enabling the survivor to learn to manage this adverse effect.

**PGHD Can Help Survivors and Providers Recognize Unique Health Problems**

PGHD tools can help cancer survivors recognize physiological phenomena that are unique to their treatment and incompletely described in the literature, or that manifest over time in unanticipated ways. People who have undergone chemotherapy, particularly uncommon combinations of drugs or drugs that are no longer used to treat the cancer they had, may have little information on which to base their expectations about potential health problems and needs. In many cases, the healthcare system neither acknowledges nor supports cancer survivors’ invisible work.

**PGHD Facilitates a More Accurate Representation of Survivors’ Quality of Life**

Quality of life is among the most difficult measures for providers to assess, which results in physicians using patients’ functional status as a proxy for their quality of life. Using PGHD as part of a clinical assessment can help cancer survivors and their healthcare providers take into account survivors’ perceptions of their quality of life when making decisions about the survivor’s care. Patient-determined quality of life is important because, when no treatment option offers a clear advantage in outcomes, patients make decisions about their care based on the expected quality of life that would result from each treatment option.

**PGHD Makes Visible the Work That Survivors Do to Manage Their Condition and Life**

Patients’ invisible work has been defined as the portion of their effort that remains hidden because it occurs behind the scenes, between clinical encounters, or amidst multiple distributed actors. In many cases, the healthcare system neither acknowledges nor supports cancer survivors’ invisible work. Including PGHD in survivors’ medical records can help providers better understand how survivors manage their own health, identify opportunities for improving the survivor’s health, and strengthen the patient-provider relationship through greater shared understanding of survivors’ efforts and needs.

**PGHD Can Bridge the Gap Between Clinical and Patient Expertise**

Much as providers develop expertise caring for patients through medical training and supervised practice, cancer survivors develop patient expertise while carrying out patient work. Over time, these differing approaches result in a gap between clinical and patient expertise. PGHD describes the experience of survivors in a shared language that patients and providers can use to close the expertise gap.

**Promotion of Survivor Population Health**

**PGHD Supports Development and Refinement of New Survivorship Care Models**

Because cancer survivors’ post-treatment experiences vary so greatly, no single care model is effective in all settings and for all survivors. PGHD can function as a fundamental component in the design and development of hybrid care approaches based on existing models and of new approaches that capitalize on emerging technologies. Currently, when a survivor experiences a concerning symptom, such as intermittent shortness of breath, the individual undergoes laboratory testing, and, if the test results are normal, there may be little the survivor and provider can do to address the symptom, because its cause has not been identified.

**PGHD Obtained via a Wearable Device, Daily Collection of PROMs, or Other Sources of Data Allow the Survivor and Provider to Observe the Survivor’s Health over Time, Potentially Revealing Patterns that Suggest a Pathology That Is Not Easily Identified through Laboratory Testing**

At the population level, PGHD collected longitudinally could help researchers identify when significant shifts in individuals’ health status occur (e.g., the number of years after treatment with a particular chemotherapeutic agent that peripheral neuropathy progresses to the degree that survivors can no longer adequately perform routine tasks, such as typing), which would help providers and survivors plan survivors’ care and make life decisions. Studying such quality of life outcomes is currently difficult, given the expense of conducting longitudinal clinical trials and the variation in the cancer treatment protocols that patients receive (e.g., the agent causing the neuropathy may be given with other agents on varying schedules, potentially confounding study results), but could be accomplished by analyzing PGHD. Such models differ from existing survivorship care approaches in that these models frame care as a survivor-provider partnership, rather than as assessments to be performed by providers on survivors, and extend survivor engagement beyond compliance with a survivorship care plan developed by the attending oncologist post-treatment.

**PGHD Supports the Use of a Risk Stratification Approach to Survivorship Care**

There are guidelines for developing survivorship care plans for all cancer survivors, but some research suggests that care plans do not necessarily result in improved survivor-reported outcomes. Using a risk stratification model for care planning, one suggested approach for addressing the limitations of survivorship care resources would likely result in less post-treatment care for individuals determined to be at lower risk of the need for future care. Low-risk survivors could use PGHD to track personal health parameters (e.g., exercise tolerance, episodes of extreme numbness) to identify potential treatment-related health issues.

**PGHD Offers the Opportunity to Expand Adult Survivorship Care Beyond Surveillance**

Historically, survivorship care programs for survivors of pediatric cancers involve a broad range of efforts to monitor and promote survivors’...
health, identify and manage late effects of treatment, and prevent fu-
ture primary and secondary (metastatic) cancers. Adult survivorship 
care, however, has focused more on surveillance.37 Care strategies 
that include PGHD offer a way to provide adult survivors with survivor-
ship care that is similar to the care given to pediatric, adolescent, and 
young adult survivors.

A WAY FORWARD

The evolution of technology, in particular the development and grow-
ing utilization of social media and mobile health (mHealth), is creating 
greater opportunities for the use of PGHD in long-term cancer survi-
 vorship care. Survivors are not only benefiting from wearable devices 
and mHealth apps, but also from the increased availability of patient 
portals, which may support the transmission of PGHD to healthcare 
providers. These technical advances, along with the healthcare sys-
tem’s growing emphasis on patient engagement, have created an en-
vironment in which educated and empowered cancer survivorship can 
become the norm.

In addition, using PGHD via survivor-friendly technologies, such as 
mHealth apps, may prove valuable for addressing inequalities in 
healthcare delivery. There have been studies demonstrating the ac-
ceptability of an mHealth app that aids breast health evaluations 
among ethnically diverse, older, low-income women,38 and the ac-
ceptability of an mHealth app that aids management of chronic health 
conditions among Hispanic migrant farm workers.39 In addition, transmit-
ning daily mood ratings via text messaging to a healthcare provider 
has been shown to be a proxy for clinic-based depression assess-
ments among low-income Spanish-speaking individuals who are in 
treatment for depression.40 Oncologists have reported having a lack of 
time, challenges in clarifying healthcare providers’ role, and a lack of 
reimbursement as barriers to implementing survivorship care plans,33 
and these issues will also need to be addressed with regard to tech-
nology-based approaches, to ensure that PGHD use reduces rather 
than exacerbates health inequalities. However, the oncology research 
community began exploring the use of mHealth apps to address can-
cer health disparities at an American Association for Cancer Research 
conference in 2013, suggesting that practitioners have already begun 
to examine ways to use patient-friendly technologies to expand health 
opportunities to historically underserved individuals.41

As with other forms of health information technology, standards for 
data formatting, transmission, and integration into provider-based 
EHRs are still evolving. Incorporation of multiple types of data into a 
single EHR, in an interface that facilitates reviewing and acting on the 
information contained therein by providers, in partnership with survi-
ors, has yet to be achieved. Developing a set of tools that are dedi-
cated to PGHD-generation for cancer survivorship care includes some 
risk, in that survivors may already use other devices and measures 
and may not wish to have to use further tools, which may duplicate 
data they already track. Cancer survivors may also be reluctant to 
share PGHD with their healthcare providers if they are uncertain 
whether physicians will actually use or even know how to use such 
data; if they find PROs and apps cumbersome or needlessly time-
consuming; or if they are uncomfortable using technology. Similarly, 
providers may lack the capacity to manage additional data generated 
via existing devices and measures or may be unprepared to use such 
data for planning survivors’ care. Thus, current efforts are best fo-
cused on identifying survivors’ and providers’ interest levels related to 
PGHD use and the barriers that impede the adoption of PGHD.

In addition, there is the potential for unintended consequences of 
using PGHD. Providers may be concerned about cancer survivors’ un-
realistic expectations regarding the clinical use of PGHD generated 
outside the medical environment (eg, data generated by wearable de-
vices), as well as about legal and regulatory issues related to mHealth 
apps.42 They may also fear inadvertently running afoul of the Health 
Information Portability and Accountability Act and other regulations in-
tended to protect patients’ privacy. Greater provider education regard-
ing the applicable regulations and data protection strategies should 
help ease these concerns. In addition, until the publication of a quan-
tity of peer-reviewed literature supporting the benefits of PGHD use, 
healthcare providers may fail to commit sufficient effort towards using 
PGHD to effectively benefit from it. Clinician involvement in the de-
velopment of mobile apps for cancer symptom self-management and 
post-treatment physical activity has been associated with provider satis-
faction with such tools,43,44 suggesting that providers are open to 
PGHD collection strategies when they have the opportunity to influence 
PGHD app adoption and use. Providers have also reported greater ac-
ceptance of apps that incorporate an evidence-based approach,35 in-
dicating that there is a role for well-designed mHealth tools in cancer 
survivorship care.

For their part, cancer survivors may question clinicians’ commit-
tment to use even clinician-preferred measures in the absence of visi-
ble usage of such data in their care, and may wonder whether the 
routine use of PROMs and the collection of survivor-reported data has 
any purpose beyond documentation for care reimbursement and ma-
terial for career-furthering journal publications that have no effect on 
clinical practice. If survivors’ roles in the maintenance of their own 
health via the sharing of potentially sensitive information (eg, mea-
ures of psychological status) go unacknowledged, survivors may con-
clude that their providers do not truly support PGHD efforts and 
withdraw emotionally from the survivor-provider relationship. To maxi-
mize PGHD’s potential, providers and survivors work must work in an 
environment promoting transparency, trust, and shared decision 
making in both the short term and long term. This goal is aligned with 
informaticians’ recognition of the need for patients and their caregivers 
to collaborate to improve patients’ health and healthcare.46

Other issues that will need to be addressed include patient/pro-
vider trust in the security of as well as the cost of the technology nec-
essary for PGHD collection and use, and socioeconomic disparities 
between different patients. Users of mHealth technology have demon-
strated a wide range of responses regarding the trade-offs between 
ease of use and data security,47 suggesting that consumer-driven 
strategies for PGHD development and use will be most effective when 
they are tailored to specific populations. Information security and data 
management strategies have played a prominent role in the develop-
ment of clinical and health informatics and, in light of the national pre-
cision medicine48 and learning healthcare system49–51 initiatives, will 
play an even greater role as healthcare evolves. The cost of mHealth 
technologies is frequently cited as a concern, particularly in light of its 
potential for widening the digital divide and exacerbating existing 
socioeconomic disparities.

As with other aspects of clinical care, meaningful use of PGHD for 
cancer survivorship care rests upon the determination of survivors and 
clinicians to work together to advance survivors’ health and lives at both 
the individual and population levels. The development of a foundational 
set of tools for generating, using, and re-using PGHD can come about 
only through survivors’ commitment to integrate new technologies into 
their daily lives and providers’ willingness to practice in new ways that 
bring additional dimensions to the survivor-provider relationship.

There have been several promising developments towards PGHD 
adoption/use, however. Some efforts to integrate PGHD into cancer 
care are already underway. Oncologists use the National Cancer 
Institute’s Common Terminology Criteria for Adverse Events (CTCAE) to
report symptomatic adverse events resulting from various cancer treatments, and a companion measure, the Patient-Reported Outcomes Common Terminology Criteria for Adverse Events (PRO-CTCAE), has been created to be used by patients in clinical trials. Developed using patient feedback and accessible via a web interface, PRO-CTCAE has been shown to be valid and reliable in its ability to capture outcomes as expressed by patients. PROs also have been used successfully to assess the effects of cancer-related symptoms on the health-related quality of life experienced by lung and colorectal cancer patients, as well as for other Cancer Care Outcomes Research and Surveillance Consortium initiatives. In addition, using PROs benefits survivors who undergo multiple therapy protocols over several years by helping tease out relationships between symptoms, health-related quality of life, and progression-free survival. In the PALETTE trial for soft tissue sarcoma, the use of PROs indicated that, despite greater toxicity with the use of the targeted therapy pazopanib than with the use of a placebo, health-related quality of life remained stable while conferring 3 additional months of progression-free survival (4.6 months with pazopanib vs 1.6 months with placebo). Such information is critical to regulatory bodies that assess investigational compounds, as well as to survivors and providers who must choose a new treatment approach after initial therapies failed to control a disease.

These efforts and similar work now underway demonstrate that integrating new forms of technology and new types of data into existing clinical technologies and workflows is feasible and can be successful. Despite these opportunities for advancement, the use of PGHD has yet to become a standard component of cancer survivorship care. Informaticians can overcome this deficiency by working with cancer survivors and their providers to identify ways to standardize data and streamline the integration of PGHD into EHRs, patient portals, secure web-based and mHealth devices, and other survivor-provider interfaces. Collaborations of clinicians, survivors, and informatics professionals, perhaps through organizations such as the Patient-Centered Research Outcomes Institute, have tremendous potential for optimizing mHealth technology and the user experience in support of a healthier survivor population.

The use of PGHD in conjunction with established medical screening and surveillance strategies can not only help cancer survivors and their healthcare providers improve survivors’ health at the individual and population levels, but can also strengthen the survivor-provider relationship and advance a truly patient-centered healthcare system. Advances in technology now make increasingly individualized approaches to health management possible, and, by joining clinical and patient engagement expertise, informatics professionals have an important role in facilitating that work.

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REFERENCES


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