Published in final edited form as:

Cancer J. 2011 ; 17(4): 222–230. doi:10.1097/PPO.0b013e318227c811.

Informatics Enabled Behavioral Medicine in Oncology

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Abstract

For the practicing physician, the behavioral implications of preventing, diagnosing, and treating cancer are many and varied. Fortunately, an enhanced capacity in informatics may help create a redesigned ecosystem in which applying evidence-based principles from behavioral medicine will become a routine part of care. Innovation to support this evolution will be spurred by the “meaningful use” criteria stipulated by the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, and by focused research and development efforts within the broader health information ecosystem. The implications for how to better integrate evidence-based principles in behavioral medicine into oncology care through both spheres of development are discussed within the framework of the cancer control continuum. The promise of using the data collected through these tools to accelerate discovery in psycho-oncology is also discussed. If nurtured appropriately, these developments should help accelerate successes against cancer by altering the behavioral milieu.

Informatics-Enabled Behavioral Medicine in Oncology

“Attending to psychosocial needs should be an integral part of quality cancer care. All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical care.”

- Institute of Medicine, “Cancer Care for the Whole Patient”¹

The Role of Behavioral Medicine in Oncology

For a practicing clinician, the behavioral implications associated with preventing, diagnosing, and treating cancer are many and varied.^{2–3} In a primary care setting, the challenge may be to encourage healthy behavior in reducing risks from smoking;⁴ or in providing sun safety education;⁵ or in encouraging patients to improve their diets or engage in regular exercise.⁶ The primary care physician is also at the front lines in making recommendations for age-appropriate screening,^{7–9} and fielding questions from concerned patients who express confusion over changes in screening guidelines broadcast in the popular media.¹⁰

For the oncology specialist, paying attention to the acute disruption of a cancer diagnosis on a patient’s psychological well being and social functioning requires its own vigilance and

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Disclaimers: None

Competing interests: None

sensitivity.¹ Patient's confusion can lead to missed appointments, psychological stress, or delays in assembling a cancer treatment plan, which can be especially problematic for patients and clinicians during the crucial first month after initial detection.^{11–12} Once a treatment plan is established, providing psychosocial services should be considered a standard of care;¹ yet as the support team broadens during treatment, so will the challenges of coordinating care across multiple specialists, support staff, and treatment facilities.^{11–13} Survivorship is often the most neglected phase of the cancer trajectory, yet the long-term psychological effects of dealing with posttraumatic stress, sexual dysfunction, emotional turmoil, financial issues, and the stress of constant vigilance are substantial.^{13–16}

This emphasis on the behavioral aspects of care may seem daunting to the already overburdened care team, especially in a traditional reimbursement system that emphasizes procedures over outcomes, and cure over prevention. Fortunately, there is an expansion in capacity triggered by the digital revolution and facilitated by policy changes for healthcare reimbursement that may ease the integration of behavioral support across all dimensions of care.

Behavioral Informatics within Healthcare Settings

Two reports delivered by the President's Council of Advisors on Science and Technology (PCAST) in December, 2010, speak to the promise of enhanced capacity for improving cancer care for the whole patient. The first of these, titled "*Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward*," highlighted the role that interoperable electronic health records (EHRs) will play in improving the foundation of care offered within and between healthcare settings.¹⁷ By design, the report continued to explore the emphasis placed by Congress on the "meaningful use"¹⁸ criteria for steering adoption of health information technology maintained within the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009.¹⁹

The meaningful use criteria represent a behavioral view of technology.^{20–23} Their emphasis on safety, patient engagement, care coordination, population health, and privacy/confidentiality reinforce the *sociotechnical use*²⁴ of the technology, rather than expanding on computational capacity.^{21, 25} Within cancer control, the meaningful use criteria can and should be applied to providing support for physicians, care teams, patients, and their caregivers across the cancer control continuum.

By using the term "cancer control," we refer to the multidisciplinary application of findings from the behavioral, medical, and population sciences toward reducing death and suffering from neoplastic disease.³ We recap the principal phases of the cancer control continuum in the first column of Table 1 as an organizing theme for discussing the implications for behavioral informatics in oncology. In the second column, we offer a synthesis of the primary targets to which behavioral medicine has been traditionally oriented in cancer, and in the third column we offer a view of how informatics applications within clinical care settings can help realize behavioral medicine goals relative to oncology. We offer a narrative description of each phase below. (Table 1)

Prevention and Early Detection

One of the distinguishing characteristics of the Patient Protection and Affordable Care Act of 2010 is its emphasis on providing support for preventive care.²⁶ As prelude to the Affordable Care Act, the HITECH Act was intended to provide the machinery necessary to: (a) keep track of patients' health-related information over time, thus eliminating the redundant costs associated with extraneous tests or unnecessary procedures²⁷; (b) change the process of care to prevent errors of *commission* (e.g., to prevent harmful pharmaceutical

interactions);²⁸ (c) change the process of care to eliminate errors of *omission* (e.g., promoting full compliance with screening recommendations);²⁹ (d) collect data from patients to improve care delivery within the “learning healthcare” organization;³⁰ and (e) aggregate data on populations to address issues of health disparities in cancer prevention and early detection.³¹ Taken together, these changes should shift the incentive structures for making preventive cancer care an integral part of the national system of health.³²

A clinical information system that tied together all the necessary components of care would help plug the holes, which typically emerge between recommendations for preventive behavior and follow-up.³³ Linking systems, perhaps integrated as part of the medical home architecture in primary care, would ensure that tracking systems were in place to prompt personalized contact when a loss to follow-up is detected.³⁴ Administrative dashboards could help track progress across all populations served by the healthcare system, with special outreach and policy changes recommended when disparities in prevention service utilization are detected.²³ A robust system for health information exchange across systems would help to ensure that redundant tests were not ordered, thus saving the overall system money and reducing patients’ exposure to radiating imagery or invasive diagnostics.³⁵ Case management tools for individual patients would help orient care from a fragmented, reactionary approach to a more predictive, preventive, personalized, and participatory approach.³⁶ Eventually, genetically informed risk prediction tools could be incorporated into the prevention system to reduce extraneous costs while enhancing preventive outcomes.³⁷

Diagnosis and Treatment

Once a patient is suspected of presenting with a malignant neoplasm, the need for systemic coordination and synchronized handoffs increases.² Unfortunately, disruptions within a fragmented system of care can lead to uneven quality in service delivery.^{2, 28} From a 2008 report with input from oncology experts, the perceived obstacles to achieving high quality cancer care included a lack of adherence to guidelines for diagnosis, treatment, and surveillance; insufficient teamwork and communication across the care team; lack of patient awareness and empowerment; diagnostic delays during transition periods between providers; and excessive reimbursement for treatment or over-treatment.¹² Experts have suggested ways to address some of these barriers through the use of patient navigators³⁸ and (or) making full use of interoperable EHR systems.^{12, 29}

An advantage that an interoperable EHR system brings to the treatment process is coordination of all that is known about a patient’s condition, including evaluations or self-reports of psychosocial need,³⁹ into one place. The analogy from the perspective of a patient with a complex array of medical conditions is that of a “Wiki,” that is, maintaining an electronic knowledge repository for a particular subject – in this case the patient’s condition – in a way that presents updates for virtual collaborators in the patient’s care.⁴⁰ In a clinical trial underway in Boston, at least one biomedical researcher is even investigating the utility of asking patients to review the clinical notes written by the care team after their visits.⁴¹ Doing so would inform patient about what the current diagnosis and treatment plan is for their condition, but it might even allow patients to correct reporting mistakes when noted. Deploying a fully functional EHR with a tethered access point for patients should facilitate a sense of “situational awareness”⁴² among all members of the care team, and create a sense of “persistent conversation”⁴³ in which all facets of the patient-provider (and provider-provider) interactions are recorded for review under less harried circumstances.

EHR systems can also reduce errors through a careful monitoring of potentially harmful treatment interactions, by prompting users or caregivers in real time to improve adherence to treatment protocols, and by monitoring treatment progress through remote sensors or patient-reported outcomes.⁴⁴ Thus, EHRs are not just data repositories; they are also agents

for transforming the clinical process.¹¹ By making it easier to bridge the results of medical treatments with ongoing patient reports of physical discomfort, along with impressions of social and psychological need, it should be easier to attend to the needs of the whole cancer patient as stressed by the Institute of Medicine (IOM).¹ On March 15, 2011, Senator Sheldon Whitehouse of Rhode Island introduced Senate Bill 539, titled the *Behavioral Health Information Technology Act of 2011*. One purpose was to integrate treatment of patients' physiological and psychological support needs through the incentives structures built into the meaningful use component of the HITECH Act.

Survivorship and End of Life

In its report on cancer survivorship, the IOM pointed to four dimensions of patient need that health systems should begin to address.¹⁶ The first was to prevent the recurrence of the original cancer, and to forestall the development of any new cancers. Prevention efforts among cancer survivors can be especially challenging, however. Not only is the patient at a greater statistical risk for disease as a result of the first cancer, but the psychological trauma of experiencing a life-threatening disease can itself lead to unhealthy behaviors from smoking to excessive eating.⁴⁵ Building a system that follows best behavioral guidelines for adherence to prevention recommendations while keeping track of psychological needs could help steer protective efforts for survivors.^{46–47}

The second related need is to establish a surveillance plan to monitor for recurrence, new cancers, late stage complications from treatment, and just as importantly, late stage psychological effects after treatment. Here the communication problems between primary and oncology care, across provider systems over time, and across physicians within the same provider are especially keen.^{34, 48} As one cancer survivor described it: "I have not found a provider who understands both sides of my current needs ... Internists do not understand my cancer and oncologists do not understand my non-cancer health maintenance needs, such as monitoring cholesterol and blood pressure."⁴⁸ Representing the data fields to accommodate both sides of a survivors' care plan, and then building decision support tools to remind all members of the team when check-ups are needed, is one way that EHRs can help solve these problems.⁴⁹ Prompts to monitor for psychosocial effects (e.g., sexual dysfunction, marital discord, depression) should be included.^{50–52}

The third need, once a system has been created to monitor for late stage effects, is to intervene as appropriate. As with treatment, the inclusion of a proactive plan for dealing with late-stage effects will be an important part of the EHR as it passes between systems.⁵³ Accountability tools, checklists, and reminders can be integrated into the system to ensure safe and timely delivery of services. In creating these tools, researchers should attend to the visual design of computer interfaces so that the data accumulated over a lifetime are portrayed informatively and choices are presented effectively to users.⁵⁴ It also will be incumbent on designers to keep the needs of patients with long-term care needs firmly in mind.⁵⁵ Systems that demand too much of users, require too much time or learning to use, are littered with legal and medical jargon, or are simply difficult to navigate, can have deleterious consequences for proactive intervention.^{25, 55–58}

The fourth need is to provide better coordination between specialists and primary care providers. Health systems data have revealed a recurring confusion among providers over which member of the care team is responsible for surveillance, recurring health maintenance, treatment of co-morbid conditions, and treatment of late-complications.⁴⁸ Developing a survivorship care plan and then making it accessible electronically to all members of the current care team, to the potential members of future care teams, to the patient, and to supportive family members (especially in the case of childhood cancer) is one way of dealing with the problem.⁵³ Allowing permissible members of the team to annotate

the electronic chart over time, as with treatment, might be another way of accumulating knowledge about the complexities of living with the sequelae of cancer over time.⁴⁰

Even at the end-of-life, a comprehensive EHR system can provide support to the patient and family members, which is often missing in current systems of care.⁵⁹ Pain management issues are especially salient to patients at end-of-life⁶⁰, as are coordination issues as patients and their families deal with the realities of hospice care, legal services, bereavement counseling, in-home services, and pain management.⁶¹ At this stage, the need for “high touch” –perhaps facilitated by the coordinating power of “hi tech” – should be an important priority. No system should be an obstacle for a patient’s psychosocial needs at any point in the cancer trajectory, but this may be especially true for the natural transitions accompanying end-of-life.^{3, 59}

Behavioral Informatics outside of the Healthcare Setting

The second PCAST report reminds us that all patients live within a broad information ecosystem, which also merits attention as a means for providing patients and their families with a safe and protected web of support over their life spans.⁶² As some observers have noticed, changes in the broader information system have been spurred by larger social, professional, and economic trends in modern medicine.^{63–65} Following the lead of other economic sectors (such as travel and banking), there is a trend toward greater commoditization of medical services with an increased emphasis on patient self-service, online consultation, and “retail medicine.”⁶⁴ As the demand for medical services outweighs the supply of primary care physicians, a development likely under provisions of the Affordable Care Act, there will be more reliance on paraprofessional services and machine-aided diagnosis.^{26, 64} As the tech-savvy baby boom generation retires and experiences disability and illness, demands will increase for in-home healthcare and for technology-assisted self-care.^{64–65} Finally, as the digitally accustomed Gen Y and Millennial generations mature, demands for online health data, social media environments, mobile apps, texting, and collaborative decision-making will expand.^{63, 65}

Each of these trends will have implications for behavioral medicine in oncology. As within clinical practice, there will be significant sociotechnical²⁴ – or human factors⁶⁶ – challenges to resolve when considering the influence of these technologies on prevention, early detection, diagnosis, treatment, survivorship, and end-of-life.^{54, 67} Unlike developments in the clinical setting, however, there will be even less control over the unintended consequences of maladaptive growth in the consumer sphere. Vigilance on the part of public health researchers, policy makers, physicians, regulatory bodies, and the public-at-large will be required to monitor the effects of change in the consumer space, and then to marshal those changes toward positive ends. In Table 2, we consider how developments in the broader information ecology can be harnessed for the benefit of behavioral medicine in oncology. (Table 2)

Prevention and Early Detection

Many of the most notable successes in cancer prevention and early detection have occurred in the public health arena. The ongoing drop in adult smoking from over half of adults in the U.S. in 1963 to 20.6% in 2009, with a concomitant drop in lung cancer mortality stands as a testament to public health communication campaigns, along with progressive policy making.⁶⁸ The notable spike in colorectal cancer screening rates when Katie Couric took to the airwaves to emphasize the importance of colorectal cancer screening stands as a positive example of the effect mass media can have on public behavior.^{69–70}

What may be new this time around is the market being built around consumer applications for health which can be used to motivate individual and collective action.⁷¹ Web tools have been developed to help smokers take active control of their nicotine addiction,⁷² to assist dieters in monitoring their caloric intake,⁷³ to guide sun seekers in reducing their exposure to UV radiation,⁷⁴ along with countless other examples.⁷⁵ As mobile devices come online, researchers are beginning to investigate the efficacy of using text messaging, pedometer readings, GPS positioning information, mobile self-management apps, and other types of functionality to extend the reach, efficiency, and effectiveness of cancer prevention efforts.^{76–77}

Another shift in the information ecology surrounding prevention is the availability of information, from all sources, to consumers in close to real time. The days, it seems, of waiting methodically until all of the data are available from relevant epidemiologic studies, Phase III clinical trials, and scholarly consensus panels *before communicating* to the public are over. In July of 2002, when the National Institutes of Health terminated the Estrogen + Progesterone study arm of the Women's Health Initiative because of risks for breast cancer, thousands of women flooded the publishing journal's website to download the original article before the paper copy of the journal had even been delivered to their gynecologists. Thousands more terminated their hormone replacement therapy almost immediately, based on the information they found online and as circulated through radio and television.^{78–79}

One implication for cancer care providers is that patients are likely to continue showing up to their appointments with information culled from the Internet; information that up until recently would have only been available within the protected confines of the patient-clinician interview.^{80–81} Even showing up to appointments with genetic risk information will likely become more common as online genetic sequencing companies (e.g. www.23andme.com; www.genewiz.com) become commonplace.⁸² Although disconcerting to many health professionals at first, new behavioral data suggest that it is possible to mitigate the potential confusion that direct-to-consumer medical advertising can cause by debriefing the patient through education and counseling.⁸² Data from the Health Information National Trends Survey suggest that patients' trust in their physicians may actually be rising as they turn to medical experts for help in deciphering what they find online.⁸¹ Web service developers in oncology can facilitate the exchange by organizing printable material with clear attributions to source, so that the patient and physician can put the details of the material into context.

Diagnosis and Treatment

As the information ecology outside of healthcare becomes more sophisticated, some software companies have taken on the task of coordinating input from diverse sources into consumer-facing applications for use by consumers.^{17, 62} The concept is similar to the development of many of the consumer-oriented financial management software products on the market today. Many of these new financial management products connect securely, confidentially, and seamlessly to the transactional data flows of online banking and investment companies. Software developers can then embed decision support tools, online tracking, bill paying, financial planning, product ordering, and other services within their products. Users can take advantage of these tools and the secure data streams on which they operate to get in better control of their finances. The more successful programs can even guide the average consumer through the highly complex decision processes that would otherwise require advanced skills or training. Alerts can be sent to the software, or in parallel as a text message or recorded voice response, when an anomalous spending event occurs, enabling the user to intervene quickly in the event of fraud or insufficient funds.

The same level of cognitive support could be built into the consumer-facing applications constructed on top of similarly protected health information exchanges. Drawing in data seamlessly from a host of input streams, a consumer-oriented Personal Health Record (PHR) could help patients organize all the facets of their oncology care, to engage proactively in self-management during care, and to provide an external safety check on missed opportunities for intervention.^{83–85} At the diagnostic phase, the emphasis will be on coordinating input and answering patient questions responsively. These tools can also help prepare the patient for the inevitable decisions that will come once a diagnosis is reached and a treatment plan is derived.⁸⁶

If the treatment plan is “watchful waiting,” then the monitoring tools should help guide future interactions with the healthcare system to remain vigilant for signs of aggressive growth. If a more aggressive treatment plan is chosen, then patients will want to be given access to educational materials about their condition in order to make an informed decision and to remain adherent to therapeutic demands once treatment starts. The American Society of Clinical Oncology, for example, has assembled a comprehensive set of materials on melanoma, which it has assembled into a consumer-facing, targeted therapy finder.⁸⁷ The tool allows patients to participate actively in creating a customized care plan for themselves, and to stay abreast of potentially relevant clinical trials.

Social media tools, such as the social support site *CaringBridge.org*, can be used to connect patients to their families and support groups at a time when emotional and instrumental support may be most needed.⁸⁸ These sites make it easy for a patient to communicate broadly with their whole social support system at times that are most convenient for them, and for caring others to offer their support in ways, which are not intrusive.⁸⁹ For patients undergoing treatment, even something as fundamental as having access to synchronous (through telephone) and asynchronous (through texting and email) channels of communication may make a big difference in clarifying problems as they emerge and in answering questions about care. From studies conducted within the context of the Comprehensive Health Enhancement Support System (CHESS), the creation of a protected feedback loop between cancer patients and their care teams resulted in a statistically significant survivorship benefit. Using external technologies to protect the communication line between patients and their support teams should yield patient benefits not just in terms of satisfaction but in quality of life and medical outcomes.⁹⁰

Survivorship and End-of-Life

The use of a free-standing PHR may have even greater applicability to cancer survivors, whose reliance on a cohesive healthcare system may have evaporated with the realities of transition from acute care to chronic vigilance.¹⁶ Some initial experiments have demonstrated how a Web-based care plan can provide persistent and ubiquitous access to a pediatric patient’s full treatment history online, and how it can help inform future interactions with clinical staff by providing an accurate record of care for input into a history and physical. The external availability of a medical history stored on the Web (or in current parlance, “in the cloud”) can help make up for the absence of a fully interoperable EHR oncology module. It can fill the vacuum, as suggested by authors of the second PCAST report, of an ongoing EHR covering the patient’s life span.

Social media sites, listservs, discussion groups, and online patient portals can offer continuing support for cancer survivors throughout the life trajectory. When asked how easy it was to find information about their conditions through the HINTS survey, patients, who had transitioned beyond their treatment phase, showed mounting frustration as time progressed.^{91–92} External social support channels can help fill survivors’ needs – at least in part – by offering access to the “collective intelligence” of online communities.⁹³ This may

be especially important for populations with strong familial links. Early HINTS data suggest that when controlling for access to the Internet, Hispanic and Black communities utilize social media at an even greater rate than their White counterparts.⁹⁴

When patients reach end-of-life, the external social network can offer solace and meaning both to patients and to their support groups.⁵⁹ Oncologists, social workers, and other care professionals can likewise turn to online communities for best advice on how to deal with the difficulties of end-of-life care.⁹⁵ Public discussions of end-of-life issues, although frequently controversial, can in some cases lead to a cultural awareness of systemic problems. Publishing and discussing government-collected data on trends in pain management approaches across countries, has led to substantive revisions to policies on the availability and regulation of pain ameliorating medications.⁹⁶

Implications for HIT for Accelerating Discovery in Psycho-oncology

Earlier, we discussed the role of the electronic health record (EHR) for improving patient outcomes by enabling alterations within systems of care.^{30, 83} The EHR also provides the opportunity to expand knowledge about the patient for research purposes.^{97–98} Informatics, medicine and behavioral science experts are discussing the feasibility of including patient reports on psychosocial measures as part of the EHR.⁴⁹ In collaboration, NCI, the Office for Behavioral and Social Science Research and the Society of Behavioral Medicine have identified essential psychosocial constructs, such as diet, physical exercise, demographic characteristics, stress, depression and anxiety, and (brief) candidate instruments.⁴⁹ Besides providing valuable data for diagnosis and treatment decisions, such measures also would provide a rich source of psychosocial data for research purposes, because there is the potential for possible links (while maintaining human subjects protections) to medical and physiological variables. The expansion of data collection and availability across levels (biological, medical, psychosocial and demographic) could increase data liquidity exponentially. Assuming technological feasibility, the opportunity for medical, epidemiological and biobehavioral scientists to link urine and plasma assays and tissue specimens with psychosocial data would facilitate the pursuit of a wide range of questions about the role of behavioral factors and biological processes (such as inflammation and tumor progression). Currently, research in psycho-oncology examining causal pathways between biologic specimens and assays and behavioral and psychosocial variables⁹⁹ is still in its early stages partly because each investigative team must start from scratch (unless they happen upon an existing and relevant potential data set, which was designed for other purposes). The EHR brings an enhanced and exciting capability to link bio-, psycho-, and social variables to make the biopsychosocial model, envisioned by Engel¹⁰⁰ in 1977¹⁰¹, a reality for science and practice.

The EHR's potential for connecting data from multiple levels, is especially relevant to growing interest in gene X environment interactions. For example, Caspi et al.¹⁰² identified a genetic factor moderating the susceptibility to depression after stress. This discovery was only made possible because of the existence of a prospective study of a large sample of adolescents in New Zealand for whom both psychosocial and genomic data were available. The availability of such data sets is currently rare, however, the EHR could serve as the platform for connecting genomic and behavioral data with health outcomes.

It is difficult, in fact, to imagine how genomics could reach its full potential in the absence of data streams from multiple (medical, physiologic, behavioral, demographic) levels of analysis. The promise of personalized healthcare solutions requires the delivery of effective therapies that are tailored to the exact biology or biological state of an individual. In an editorial in *Molecular Systems Biology*, Nicholson¹⁰³ observed, "Ideally, this would involve

a system of patient evaluation that would tell clinicians the correct drug, dose or intervention for any individual before the start of therapy,” (p. 1). Relying, however, only on modeling biofeatures in relation to outcome to create patient stratification without consideration of the behavioral context ignores genomic X environment interactions. Integration of the EHR, including behavioral and physiologic variables, and the ‘omics’ approaches (pharmacogenomics, pharmacoproteomics and pharmaco-metabonomics) may afford the predictive power for personalized medicine to make significant strides in public health.

There are of course, connectivity challenges of a technological and logistical nature and additionally human protections and privacy challenges, but none are insurmountable. The EHR provides the opportunity to create a hub for scientists and practitioners who work at different levels of analysis, with the EHR simultaneously serving dual functions for the “bench” and the “bedside.”

The EHR also may serve as a health journal for the patient, enabling their own examination of data for personal discovery. For the chronically ill or complex patient recalling their previous medical status, the treatment details and temporal sequence over lengthy periods can be problematic. At trying medical times, the patient and support providers are often too preoccupied to have the opportunity to keep orderly records of the experiment. The EHR, however, can provide a user-friendly and accessible detailed record of all of this information.

Accelerating Success against Cancer Now

When asked to identify a path forward for achieving real gains against cancer now, directors of the NCI-designated cancer centers argued for creating a system in which everything currently known about this insidious set of diseases is uniformly and equitably throughout the system. This means applying what we know first in prevention and early detection, the center directors argued, as that is where we will make the biggest impact in terms of lives saved and suffering averted. It also means applying what we know about efficient and accurate diagnosis, personalized treatment, and ongoing vigilance during survivorship. Consider the stakes in cancer care. Even a 1% reduction in cancer mortality would result in a \$400 billion savings to the nation’s bottom line, according to the projections of health economists at the University of Chicago.¹⁰⁴

The key to improving translation systemically, according to the arguments made within the PCAST^{17, 62} and other reports^{28, 104–106}, is to create a new foundation of fluid health information: one that is engineered to improve medical outcomes by supporting the cognitive and behavioral needs of physicians, patients, and their caregivers. This will be the next horizon for informatics enabled behavioral medicine in oncology.

Acknowledgments

Complete Funding Declaration: No relevant funding to report.

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Table 1

Supporting behavioral needs across the cancer continuum from within Healthcare.

	Cancer Control Goal	Healthcare Informatics Systems
Prevention	<ul style="list-style-type: none"> Promote health protective lifestyle Offer support services for behavior change Personalize communication based on molecular, genetic, behavioral profile 	<ul style="list-style-type: none"> Provide educational materials through patient portals, “information prescriptions” Embed evidence-based support applications tethered to patient data; link to services Maintain an ongoing personalized prevention plan, informed by genetic tests, biomarker assays, personal history, and patient- contributed input.
Early detection	<ul style="list-style-type: none"> Ensure adherence for recommended screenings Promote informed decision making Interpret findings from self-vigilance Ensure adherence to follow-up plan 	<ul style="list-style-type: none"> Develop profile-driven “reminder systems” to prompt healthcare team and patient Create user-friendly decisional architectures to prompt action in line with patient values Offer self-paced interpretative information online with inquiry capability to care team. Offer escalating support to patient and care team to remove barriers, incent adherence
Diagnosis	<ul style="list-style-type: none"> Coordinate tests, reduce financial/ invasive burden to patient Support timely, sensitive communications Offer psychosocial support services 	<ul style="list-style-type: none"> Build data sharing and secure messaging tools to facilitate timely transfer of data for referrals. Perform systems analysis to reduce burden. Conduct user-testing on methods for communicating diagnostic results to patients. Offer easy access to support services through online service-request functions.
Treatment	<ul style="list-style-type: none"> Organize a treatment plan that is safe, effective, and congruent with patient values Facilitate decision making throughout course of treatment Control pain, monitor for side effects Facilitate social support 	<ul style="list-style-type: none"> Create a persistent, transparent version of the treatment plan that can be shared easily with the patient and members of the broader caregiving team. Offer 24 X 7 access to supportive information relevant to the treatment plan; offer communication channels for advice. Build mechanisms for ubiquitous connectivity between the patient and care team. Expand system coverage to include the patient’s family.
Survivorship	<ul style="list-style-type: none"> Prevent recurrent & new cancers, late effects Monitor for cancer spread; assess for psychosocial late effects Intervene for consequences of cancer and its treatment Coordinate between specialists and primary care providers 	<ul style="list-style-type: none"> Personalize prevention recommendations to take into account adjusted risk. Establish a monitoring plan that can sustain surveillance triggers reminders across the full system of care. Include accountability tools, checklists and reminders systems to ensure treatment plan fulfillment. Enable ability to update survivorship care plan and to retain historical revisions.
End of life	<ul style="list-style-type: none"> Preserve dignity, quality of life Offer palliative care in accordance with patient’s values Offer bereavement counseling; attend to family’s social, financial, and legal needs 	<ul style="list-style-type: none"> Organize system around patients’ needs for autonomy and personal connections. Establish a reporting channel for monitoring palliative care needs; expand connectivity to include ordering capacity for pain control. Offer linkages to additional support services through electronic messaging, and service fulfillment.

Table 2

Supporting behavioral needs across the cancer continuum outside of Healthcare.

	Cancer Control Goal	Networking & Information Technology
Prevention	<ul style="list-style-type: none"> Promote health protective lifestyle Offer support services for behavior change Personalize communication based on molecular, genetic, behavioral profile 	<ul style="list-style-type: none"> Stimulate development of evidence-based, behavioral change tools Offer quick links, mapped resources, and online directories to support services Cultivate an interoperable eHealth ecosystem in which data from clinical information systems, pharmaceuticals, medical devices, etc., can be brought into PHRs for decision support
Early detection	<ul style="list-style-type: none"> Ensure adherence to recommended screenings Promote informed decision making Answer questions from self-vigilance Ensure adherence to follow-up plan 	<ul style="list-style-type: none"> Provide informational and motivational resources, linkages to service, Nurture development of educational materials, decision-support tools, and product reviews Offer clarifying information, interpretive decision support, linkages to professionals Incorporate notification procedures to accountable care organizations, build in reminders on patient side
Diagnosis	<ul style="list-style-type: none"> Facilitate timely, accurate Diagnosis Coordinate tests, reduce financial/invasive burden to patient Offer psychosocial support services 	<ul style="list-style-type: none"> Shore up the information supply chain to ensure prompt fulfillment Channel data through health information exchange to eliminate redundancy, provide situational awareness, inform patient Trigger proactive attention to psychosocial issues at early stages of diagnosis
Treatment	<ul style="list-style-type: none"> Organize a treatment plan that is safe, effective, and congruent with patient values Facilitate decision making throughout course of treatment Control pain, monitor for side effects Facilitate social support 	<ul style="list-style-type: none"> Ensure safety and standards through regulatory boards (FDA & NIST); create decision support tools to organize best treatment; provide opportunities for clinical trials Protect data flows to/from clinical staff, support services, similarly situated patients; allow for self-monitoring; provide decision support tools Provide for secure linkages between pharmacies, clinical staff, patients, care givers Stimulate social networking applications around behaviorally documented needs for social support
Survivorship	<ul style="list-style-type: none"> Prevent recurrent & new cancers, late effects Monitor for cancer spread; assess for psychosocial late effects Intervene for consequences of cancer and its treatment Coordinate between specialists and primary care providers 	<ul style="list-style-type: none"> Facilitate transportability of survivorship care plan, encourage social comparison linkages Update screening recommendations in PHRs; provide self-evaluation tools for late-stage effects (PTSD); encourage discussion, linking Ensure proactive care through coordinated messaging; offer decision support tools along with disease self-management tools Address coordination through health information exchanges; offer monitoring tools to encourage patient and caregiver supervision
End of life	<ul style="list-style-type: none"> Preserve dignity, quality of life Offer palliative care in accordance with patient's values 	<ul style="list-style-type: none"> Take advantage of tools & specialists to teach coping, connect family, and guide decisions Design specialized consumer informatics tools for palliative care, including pain relief, symptom reporting, & ameliorative ideation

	Cancer Control Goal	Networking & Information Technology
	<ul style="list-style-type: none">• Offer bereavement counseling; attend to family's social, financial, and legal needs	<ul style="list-style-type: none">• Offer support and linkages to family members as they engage in the difficult tasks of grieving, disposing of the estate, organizing memorial services, and life planning