



HHPR

Harvard Health Policy Review Volume 14 Issue 2



**Generating
Signal from Noise:**

Big Data's Big Challenge

The Development of MyCancerJourney and the Incorporation of Predictive Analytics to Improve Cancer Patient Care

Jay F. Piccirillo, MD^{1,2}, Dorina Kallogjeri, MD, MPH^{1,2}, Sara Kukuljan, BS RN CCRC¹, and Robert Palmer, MBA³

Newly diagnosed cancer patients seek relevant and accurate information regarding prognosis, treatment effectiveness, and quality of life. The current evidence base for cancer care is not designed to answer many of these questions. MyCancerJourney is a web-based portal to capture, organize, analyze, and present patient-specific information for newly diagnosed adult cancer patients at the time of diagnosis and for cancer patients throughout their entire survivorship experience. MyCancerJourney is designed to be the electronic hub of the cancer patient's experience and can support the type of patient-centric model of cancer care that health care reform demands and cancer patient groups advocate.

AS THE POPULATION AGES and more Americans are diagnosed with cancer, the challenges of cancer diagnosis, provision of accurate prognostic information, and treatment choices will become even greater than at present. In 2014, approximately 1.7 million Americans developed a new cancer and nearly 14.5 million Americans are living with a diagnosis of cancer; in 2024, it is expected that 19 million Americans will be living with a diagnosis of cancer.^{1,2} As a result of the large number of newly diagnosed cancer patients and cancer survivors, billions of dollars will be spent on cancer treatments and survivorship issues. Unfortunately, in many cases, these expenditures will not result in the expected outcomes.^{3,4} We believe a significant reason cancer care is not producing the benefits we expect is that physicians cannot access relevant evidence to permit personalized treatments and to provide evidence-based care. Equally important, patients cannot benefit from the wisdom of the experience of millions of other cancer patients due to inadequate information systems, data capture, processing, and sharing.

A cancer diagnosis is terrifying and the treatment choices are complex with profound survival, quality of life, and economic implications. Patients and their families are provided with complex and often unclear or contradictory information and are therefore left to make overwhelming treatment decisions without adequate data. Currently, available evidence-based information does not support a personalized treatment plan and the evidence base of cancer care is not sound. There are multiple reasons why the evidence base for cancer care is unsound. The prognostic estimates and treatment decision-making in cancer care are primarily based on the results from clinical trials and statistics published by the National Cancer Institute⁵ and the American Cancer Society.¹ Often, these data relate mortality to site and morphologic spread of a tumor at the time of diagnosis and fail

to include patient-specific factors, such as patient age, gender, comorbidity, and cancer-related symptom severity.⁶ As a result, survival among participants enrolled in clinical trials is often found to be significantly different from patients with similar stage cancer enrolled in observational studies.⁷⁻¹² The low enrollment of and participation by newly-diagnosed cancer patients in clinical trials, estimated to be approximately 4% of adult cancer patients, is described as a national health issue and undermines the usefulness and generalizability of clinical trial results.¹³⁻¹⁵ The low participation by ethnic and racial minorities is very concerning since members of these groups generally experience disproportionately higher mortality rates relative to the entire U.S. population. The lack of widespread participation in clinical trials thus leads to problems in the scientific quality of the research, generalizability of the results¹² and speed of scientific discovery.¹⁶⁻¹⁸ Additional problems with clinical trials serving as the evidence base for cancer care result from the fact that clinical trials are not designed to provide prognostic information and rarely incorporate quality of life and other patient-reported outcome measures. And finally, the well-documented problem of publication bias prevents physicians and patients from understanding the true risks and benefits of various treatments.¹⁹

Today, healthcare providers and their patients do not have access to the trusted, relevant clinical information required for informed treatment decision-making. As a possible solution to the lack of generalizability and applicability of clinical trial results to individual cancer patients, Elting et al¹² encouraged the use of population-based trials of effectiveness among "all comers." Giving suitable attention to the fundamental clinical and prognostic distinctions among different patients with similar cancers, the study of the outcomes of patients treated in their natural clinical setting will provide patients and

physicians with the critical information needed for truly informed clinical decision making.

Description of MyCancerJourney

MyCancerJourney is a web-based portal to capture, organize, and present patient-specific information for newly diagnosed adult cancer patients at the time of diagnosis and throughout the entire survivorship experience. MyCancerJourney consists of three separate and unique programs: MyInsights, MyJournal, and MyCommunity. Trained cancer navigators are available to assist users with supplying the cogent information and understanding the various outputs from MyCancerJourney.

MyInsights is an interactive predictive model that generates patient-specific survival curves for newly-diagnosed adult cancer patients. The overall survival estimates are based on the Cox proportional hazards analysis of the outcomes of patients derived from multiple leading cancer centers in the U.S. Personalized survival curves based on demographic, clinical, and tumor characteristics are the initial display of survival estimates. To initiate the personalized survival curve presentation, the user provides the appropriate values for the cogent prognostic factors (e.g., age, gender, race, comorbidity score, cancer site, cancer stage, tumor grade, and, where appropriate, tumor markers). On-line guidance is provided throughout the portal for explanation and use of medical terms. The survival curve is presented as a typical x-y graph with survival duration, in years, on the x-axis and survival percentage on the y-axis. A comparison age- and gender-matched survival curve for the total population appears in each patient-specific survival graph. In a consecutive step, the impact on survival of up to four different treatment options is displayed. Upon each "click," a pictograph appears and provides the survival estimate in a format different from the survival curve and a text box provides the script that explains, in a patient-friendly language, the information provided in the graph. The primary goal of the presentation is to allow the user to compare survival outcomes for different treatment options among patients with similar cogent prognostic factors. When combined with functional well-being, quality of life, and financial information for each treatment option, MyInsights will allow for more comprehensive assessment and appropriate patient-specific decisions.

MyJournal is where patients provide basic demographic, clinical, tumor, treatment, functional well-being, and quality of life

1 Department of Otolaryngology-Head and Neck Surgery, Washington University School of Medicine, St. Louis, Missouri, U.S.A. Phone: (314)362-4125, Fax: (314)362-7522

2 Clinical Outcomes Research Office, Washington University School of Medicine, St. Louis, Missouri, U.S.A. Phone: (314)362-4125, Fax: (314)362-7522

3. PotentiallyMed, 901 South Mopac Expressway, Plaza One, Suite 300, Austin, Texas, U.S.A. Phone: (512)708-9000, Fax: (512)708-9018

information. Patients record their journey from diagnosis through survivorship and can compare their experience with patients with similar cancers and demographic and prognostic factors. In addition, patients participate in data collection that will help other cancer patients understand the benefits, risks, side effects, and outcomes of various cancer treatments. The conceptual model for the development of MyJournal is based on the framework for cancer comparative effectiveness research developed through the review of current models and semi-structured discussions with clinicians.²⁰ The cogent data is collected through the use of discrete modules, consisting of a limited number of questions and utilizing specially designed drop-down and fill-in prompts, that were created to capture the cancer care continuum from the patient's perspective. The stored data is then available for individual patient reporting or as part of group data. MyJournal was designed to capture, aggregate, and share large amounts of cancer information on the premise that collective wisdom can lead to profound improvements in cancer care.

MyCommunity is a supportive, online social networking community for users to meet, share ideas, gain resources, and manage and cope with the issues related to cancer and its treatment. MyCommunity allows the user to create personalized communities based on type of cancer, age, gender, and location along the cancer care continuum. In this way, the members of the community are better able to understand the user's situation, offer valuable treatment advice, and insights. MyCommunity transforms cancer patients and survivors into advocates and "peer coaches"; every member can ask questions and offer neighborly advice and support.

There are multiple challenges facing the development and widespread integration of MyCancerJourney into patient care. The first is obtaining continuous feeds outcomes data from more providers across the country to enhance the power of our predictions. Second, to consistently collect complete patient-reported outcomes and treatment information has historically been a challenge. We will work on novel approaches to obtain patient-reported information in a consistent fashion. Third, to model the cancer patient experience in MyCancerJourney takes considerable knowledge of clinical cancer care and remaining up-to-date with changes. Fourth, there will be the need to monitor the information shared on MyCommunity as it is likely be of a sensitive nature and defining what is suitable content for public consumption will require ongoing thoughtful review and standards. And finally, to ensure that newly diagnosed cancer patients and their families are aware of MyCancerJourney.

Conclusion

MyCancerJourney is a cloud-based advanced

analytic platform that provides a patient-friendly environment to utilize data already contained within hospital-based tumor registries, capture patient-specific demographic, clinical, treatment, and outcome information, and provide this information back to patients to use in a variety of ways, including comparative treatment effectiveness assessment. All collected data and patient-reported outcomes, including periodic follow-up assessments of general health, disease-specific functional status, quality of life, and satisfaction with care are stored "in the cloud" within secure servers and displayed in graphic formats that allow ease of understanding and interpretation.

MyCancerJourney leverages the power of



Dr. Piccirillo is Professor and Vice Chair for Research in the Department of Otolaryngology-Head and Neck Surgery at Washington University and Co-Director of the Cancer Quality Improvement Committee of the Siteman Cancer Center. He has conducted extensive research into the incorporation of comorbidity information into cancer statistics.



Dr. Kallogjeri is the Research Statistician in the Department of Otolaryngology-Head and Neck Surgery at Washington University. She has over 12 years of experience in clinical research. Dr. Kallogjeri is the instructor for the introductory and intermediate level statistical courses taught for pre- and post-doctoral students.

collective wisdom along with the power of predictive analytics to create a paradigm shift in cancer care by empowering patients with unbiased treatment and outcome information to support more informed decisions. MyCancerJourney will provide the patient-centric model of cancer care and ensure the support that health care reform demands and cancer patient groups advocate. We believe the connectedness of cancer patients that results from the use of these web-based tools will empower patients during their treatment and survivorship experience. In addition, the information captured in MyCancerJourney will help and support other cancer patients in important and previously unimagined ways.



Sara Kukuljan, BS, RN, CCRC is the Research Compliance Coordinator/Educator for the Department of Otolaryngology at Washington University School of Medicine in St. Louis. Ms. Kukuljan is a Registered Nurse, Certified Clinical Research Coordinator, and serves as President of the Greater Missouri Chapter for the Association of Clinical Research Professionals.



Mr. Robert Palmer, MBA is President and CEO of PotentiaMetrics and has over 20 years of CEO experience with startup, growth stage, and established companies. He conceived and led the development of the firm's PotentiaMED analytics products, including comparative effectiveness analysis and predictive analytics for clinical and health economic outcomes.

1. Siegel R, Ma J, Zou Z, Jemal A. Cancer statistics, 2014. *CA Cancer J Clin.* 2014;64:9-29.
2. DeSantis CE, Lin CC, Mariotto AB et al. Cancer treatment and survivorship statistics, 2014. *CA Cancer J Clin.* 2014;64:252-271.
3. Brawley OW, Goldberg P. How We Do Harm. A doctor breaks ranks about being sick in America. New York, NY: St. Martin's Griffin; 2011.
4. Leaf C. The Truth in Small Doses. Why We're Losing the War on Cancer-and How to Win It. Simon & Schuster; 2014.
5. U.S. Cancer Statistics Working Group. United States Cancer Statistics: 1999-2011 Incidence and Mortality Web-based Report. United States Cancer Statistics. 2014. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute.
6. Piccirillo JF, Feinstein AR. Clinical symptoms and comorbidity: significance for the prognostic classification of cancer. *Cancer.* 1996;77:834-842.
7. Davis S, Wright PW, Schulman SF et al. Participants in prospective, randomized clinical trials for resected non-small cell lung cancer have improved survival compared with nonparticipants in such trials. *Cancer.* 1985;56:1710-1718.
8. Antman K, Amato D, Wood W et al. Selection bias in clinical trials. *J Clin Oncol.* 1985;3:1142-1147.
9. Bertelsen K. Protocol allocation and exclusion in two Danish randomised trials in ovarian cancer. *Br J Cancer.* 1991;64:1172-1176.
10. Braunholtz DA, Edwards SJ, Lilford RJ. Are randomized clinical trials good for us (in the short term)? Evidence for a "trial effect." *J Clin Epidemiol.* 2001;54:217-224.
11. Peppercorn JM, Weeks JC, Cook EF, Joffe S. Comparison of outcomes in cancer patients treated within and outside clinical trials: conceptual framework and structured review. *Lancet.* 2004;363:263-270.
12. Elting LS, Cookley C, Bekele BN et al. Generalizability of cancer clinical trial results: prognostic differences between participants and nonparticipants. *Cancer.* 2006;106:2452-2458.
13. Brawley OW. The study of accrual to clinical trials: can we learn from studying who enters our studies? *J Clin Oncol.* 2004;22:2039-2040.
14. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA.* 2004;291:2720-2726.
15. Stewart JH, Bertoni AG, Staten JL, Levine EA, Gross CP. Participation in surgical oncology clinical trials: gender-, race/ethnicity-, and age-based disparities. *Ann Surg Oncol.* 2007;14:3328-3334.
16. Joffe S, Weeks JC. Views of American oncologists about the purposes of clinical trials. *J Natl Cancer Inst.* 2002;94:1847-1853.
17. Swanson GM, Bailar JC, III. Selection and description of cancer clinical trials participants--science or happenstance? *Cancer.* 2002;95:950-959.
18. Newman LA, Roff NK, Weinberg AD. Cancer clinical trials accrual: missed opportunities to address disparities and missed opportunities to improve outcomes for all. *Ann Surg Oncol.* 2008;15:1818-1819.
19. Easterbrook PJ, Berlin JA, Gopalan R, Matthews DR. Publication bias in clinical research. *Lancet.* 1991;337:867-872.
20. Carpenter WR, Meyer AM, Abernethy AP, Sturmer T, Kosorok MR. A framework for understanding cancer comparative effectiveness research data needs. *J Clin Epidemiol.* 2012;65:1150-1158.