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## A vision for using online portals for surveillance of patient-centered communication in cancer care

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### Abstract

The Veterans Health Administration (VHA) is charged with providing high-quality health care, not only in terms of technical competence but also with regard to patient-centered care experiences. Patient-centered coordination of care and communication are especially important in cancer care, as deficiencies in these areas have been implicated in many cases of delayed cancer diagnosis and treatment. Additionally, because cancer care facilities are concentrated within the VHA system, geographical and system-level barriers may present prominent obstacles to quality care. Systematic assessment of patient-centered communication (PCC) may help identify both individual veterans who are at risk of suboptimal care and opportunities for quality improvement initiatives at the service, facility, or system-wide level. In this manuscript, we describe our vision to implement an assessment of PCC through patient self-report to improve the quality of cancer care and other health services in the VHA. We outline a possible strategy to assess PCC that leverages the VHA's existing initiative to promote use of an online personal health record for veterans (MyHealthVet). Questionnaires administered periodically or following specific episodes of care can be targeted to assess PCC in cancer care. Assessment of PCC can also be tied to clinical and administrative data for more robust analysis of patient outcomes. Ultimately, the goal of any assessment of PCC is to gather valid, actionable data that can assist VHA clinicians and staff with providing the best possible care for veterans with cancer.

### Keywords

Patient-centered care, communication, patient experience, health information technology, patient portals, patient safety, diagnosis, cancer

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### Introduction

The Veterans Health Administration (VHA) is the United States' largest integrated health care system. Of the 8.3 million veterans served by the VHA each year, approximately 40,000 are diagnosed with a new primary cancer (about 3% of cancer cases in the United States). The VHA has over 40 comprehensive cancer centers across the country. All VHA facilities share the same electronic health record (EHR). Despite having the technological infrastructure to coordinate patient care across specialties within and across VHA facilities, veterans with cancer face a number of potential obstacles to receiving timely and effective diagnosis and treatment.<sup>1-6</sup> A recent review of root cause analyses reports of outpatient diagnostic and treatment delays within the VHA found that most delays in care were

related to communication or coordination problems.<sup>7</sup> Thus, efforts to improve the quality of communication target a leading risk factor for suboptimal cancer care in the VHA. In this manuscript, we build on current VHA initiatives to enhance patient-centered communication (PCC) and propose a vision that includes assessment of PCC through patient self-reports through online portals. This strategy could improve the quality of cancer care and other health services in the VHA from the veteran's perspective.

### The Importance of Patient-Centered Communication in the VHA

The mission of the VHA is to provide veterans with the highest quality health care, which includes not only the most up-to-date medical tests and treatments, but also

patient-centered care experiences. In support of this mission, the VHA provides access to an online personal health record (PHR) known as MyHealthVet that facilitates access to medical information and encourages self-management and active participation in care. Veterans can use MyHealthVet as a repository for personal health data (including goals, journal entries, diet plans, medical events, medications, home monitored vital signs, etc.). Additionally, MyHealthVet provides authenticated users with a secure portal to view their VHA and Department of Defense health records, schedule appointments, communicate securely with VHA clinicians, and order prescription refills. Over the last few years, the VHA has made the MyHealthVet initiative a priority, and enrollment is steadily increasing. Between 2008 and 2009, the number of registered users for MyHealthVet rose from 670,000 (12% of VHA patients receiving health care services) to 850,000 (16% of VHA patients).<sup>8</sup> As of January 2014, the MyHealthVet PHR portal has more than 2.6 million registrants (37% of the VA patient population).<sup>9</sup>

The VHA is also a pioneer in its effort to implement a patient-centered medical home through its Patient Aligned Care Team (PACT) model. Patient Aligned Care Teams aim to provide health care that is highly accessible, comprehensive, and coordinated in order to improve veterans' health and well-being.<sup>10</sup> Although PACTs are fundamentally rooted in primary care, the team approach and principles of continuous, coordinated, and comprehensive care apply to cancer and other types of specialty care as well.

The core of patient-centered care is effective communication among patients, their families, and the clinical team. Effective communication must occur at multiple levels, including conversations during the patient-clinician encounter, coordination among clinical team members, and interactions with the organization to schedule appointments, obtain pharmacy refills, and access self-care and support resources. Many of the goals for patient-centered communication are facilitated by organizational structures such as the PACTs and information technologies such as the integrated EHR and MyHealthVet.

#### ***From Vision of PCC Assessment to Reality***

One method to assess progress toward goals for PCC could be to capture patients' perceptions through self-report tools. For this purpose, we selected measures from a recent project, sponsored by the National Cancer Institute, to develop a set of measures for assessing patients' experiences of whether key patient-centered communication outcomes were achieved when receiving cancer care (Table 1; see also <http://www.pccfs.org/> for an updated list of items applied to specific stages of cancer care).<sup>11</sup> The set of 20 items tap into 6 key

functions of patient-centered communication—effective information-exchange, fostering healing relationships, making quality decisions, managing uncertainty, responding to emotions, and enabling patient self-management<sup>12</sup>—that patients have reported as being particularly important to their cancer care.<sup>13</sup> The item set was intended to function as a menu of PCC measures, the number selected would depend on the organizations needs and interests. Of particular interest in this paper are veterans' responses to items that reflect the VHA values of providing coordinated care to patients who are informed, engaged, and treated with respect (e.g., “The doctors and nurses worked together as a team in taking care of me,” “I was involved in making decisions as much as I wanted,” “I got the information I needed, when I needed it,” and “I was treated with sensitivity and respect”). Currently, there is no mechanism to measure these important outcomes at a system-wide level.<sup>14</sup> Capturing information about PCC in this manner could facilitate assessment and tracking of these crucial aspects of health care quality within and across VHA facilities.

#### ***How PCC Surveillance Would Work at the VHA***

Within the VHA, the most feasible mechanism to carry out PCC surveillance is through MyHealthVet.

Although the proportion of veterans who currently use MyHealthVet hasn't reached its maximum, the number of enrollees is steadily increasing each year, with over 2.6 million registered users in 2014.<sup>9</sup> The VHA has taken steps to integrate MyHealthVet with the EHR and to include administrative (registration, financial, etc.) and patient education components<sup>15</sup>; thus, it is possible that PCC data could be integrated within other information systems at the VHA.

The VHA has already demonstrated the potential to use MyHealthVet to assess veterans' experiences with their care. In 2007, the VHA deployed the American Customer Satisfaction Index (ASCI) through MyHealthVet to measure veteran satisfaction with MyHealthVet and assess veterans' needs and preferences for the personal health record.<sup>8</sup> The survey was initiated in the MyHealthVet portal and appeared in a separate pop-up web browser window. It was presented to site visitors based on a “customized loyalty factor” depending on previous visits to the site and achieved a higher than expected response rate. PCC surveys could be administered through a similar mechanism, either in a periodic, cross-sectional fashion or across episodes of care within patients.

We acknowledge that patients who are likely to benefit most from routine assessment of PCC outcomes might not be current users of MyHealthVet, in which case paper-based or telephone surveys methods might be appropriate. However, given current trends in

**Table 1: Patient-centered communication (PCC) assessment items**

| PCC item  | PCC function             |
|---|--------------------------|
| I was treated with sensitivity and respect.   | Relationship building    |
| I felt known as a person.   | Relationship building    |
| I felt listened to.   | Relationship building    |
| I felt comfortable asking questions and sharing my concerns.  | Information exchange     |
| I thought the doctors and nurses worked together as a team in taking care of me.                    | Relationship building    |
| My wishes were respected.   | Relationship building    |
| I got the information I needed, when I needed it.   | Information exchange     |
| I got clear, understandable information.  | Information exchange     |
| I know who to contact and what to do if I have a question or concern when I'm not at the clinic.    | Enabling self management |
| I felt comfortable bringing up anything that was on my mind.  | Information exchange     |
| Everyone was on the same page when telling me what I needed to know.                                | Information exchange     |
| I felt confident that my doctors and nurses will fully take care of my health care needs            | Relationship building    |
| I have a good sense of what we know and what we don't know about my cancer and my cancer treatment. | Managing uncertainty     |
| I got the support I needed to deal with feelings of being afraid, worried, and feeling down.        | Responding to emotions   |
| My doctors and nurses were optimistic and hopeful.  | Responding to emotions   |
| I had a clear understanding of my choices when making decisions about my cancer treatment.          | Decision-making          |
| I understand why we made the decisions we did about my cancer care.                                 | Decision-making          |
| I was involved in making decisions as much as I wanted.   | Decision-making          |
| I got the information I needed on how to take care of myself when I was not at the clinic.          | Enabling self management |
| Everyone was on the same page when telling me what I needed to know.                                | Managing uncertainty     |

utilization, we anticipate that MyHealthVet enrollment will continue to increase in all types of patient populations, including those that traditionally have not been high users of patient portals. We also anticipate that most patients who enroll will actually log on to become users of the system. For PCC surveys to yield useful data, PCC assessment initiatives must be attentive to issues of survey design and implementation through online portals, including appropriate wording, emphasizing the importance of patient feedback to improve quality of care, confidentiality of responses, and technology constraints. Below we describe how PCC assessments could be specifically applied to cancer care.

#### *Periodic PCC surveys*

The simplest use of MyHealthVet for PCC surveillance would be to use the portal to solicit veterans' feedback on their PCC experiences over a specific time interval (e.g., quarterly or annually). Although the VHA would be interested in these data for all patients, targeted recruitment of a subset of veterans who have received treatment for cancer through the VHA could be possible through EHR-based identification. Survey items could also be used to confirm that the feedback is specific to cancer care (e.g., using items inquiring about

the conditions for which patients received treatment). The survey data would reflect patients' perceptions of the degree to which PCC goals were accomplished over a given time period. The VHA, perhaps through its regional Veterans Integrated Service Networks (VISNs), could provide reports to each VHA facility on how they fared across the various PCC domains. These reports could establish system-wide benchmarks and help individual VHA facilities identify areas for improvement.

#### *PCC assessment across episodes of care*

An alternative approach to PCC surveillance, and one that largely depends on MyHealthVet integration with specific aspects of VHA data systems, would be to administer selected PCC items to patients directly following their clinical visits or after completion of key episodes of care such as surgical procedures or radiation treatments. This strategy would rely on an automatic system-generated prompt that is programmed to populate the patient's MyHealthVet with the PCC assessment (and to send a reminder if the survey is not completed within a certain time frame). Because PCC is an indicator of quality of care in and of itself,<sup>16</sup> PCC assessment could be conducted independently of other

quality measures through the EHR. This complementary approach would treat PCC assessment as a patient-reported outcome, allowing the VHA to connect patient feedback to specific aspects of care received.

A future alternative strategy could include integration of patients' responses to PCC assessment items with other measures of cancer care quality, system or provider performance, and patient outcome measures (e.g., adherence to medications/chemotherapy, appointment scheduling/cancellations, cancer screening, biomarkers). As opposed to the periodic assessment approach in which responses could easily be de-identified, this approach would require survey responses to be linked to patients in some manner. Therefore, to increase response rates, patients would need to be reassured that their feedback is important for continuous improvement in VHA health services and that their responses would be de-identified and not adversely (and could even enhance) the quality of care they receive.<sup>17</sup> This type of surveillance could extend to the entire continuum of cancer care, including prevention, screening/early detection, diagnosis, treatment, survivorship, and end-of-life care.<sup>18</sup>

#### ***Using PCC Data for Quality Improvement at the VHA***

The VHA has a strong track record of using its information technology infrastructure for quality improvement. For example, several features of the VHA's EHR are designed primarily to enhance care quality and safety (e.g., computerized provider order entry, an alert system for notifying clinicians about significant events, decision support resources).<sup>5</sup> As a quality improvement tool, MyHealth<sup>e</sup>Vet is in its infancy, yet it has considerable potential. In this section, we discuss two hypothetical but realistic examples in which assessment of PCC through MyHealth<sup>e</sup>Vet could provide actionable information for quality improvement in cancer care.

*Using telemedicine to improve coordination of cancer care.* Certain groups of veterans, such as those residing in rural areas, may face greater obstacles to care coordination due to their distance from the nearest VA facility.

Administering PCC items through MyHealth<sup>e</sup>Vet could examine the effect of residential location on PCC. Some of the relevant background information, such as residential location or distance to travel, could be automatically collected through other electronic sources and merged with self-report data. This could provide, for instance, evidence on whether cancer patients who reside a considerable distance from the VA facility tend to report lower scores on items such as "The doctors and nurses worked together as a team in taking care of me," "I got the information I needed, when I needed it," and "Everyone was on the same page when telling

me what I needed to know." Additional items with open-ended response options could allow veterans to provide comments to describe their specific experiences with care delays, wait times, and coordination among providers.

A possible solution to the problems faced by geographically dispersed veterans is the use of the VHA's videoconferencing technology (V-Tel) to coordinate care planned through the tumor boards and to provide follow-up services and care to patients in outlying areas at their local VHA health care facilities. For instance, the South Central VA Health Care Network recently established a Virtual Tumor Board (VTB) at the Michael E. DeBakey VA Medical Center at Houston, Texas. The VTB uses state-of-the-art telemedicine technology to ensure that veterans have greater access to a coordinated, multidisciplinary team of experienced and knowledgeable cancer care specialists. The VTB allows VA physicians throughout the south central United States to access the expertise of cancer experts in Houston, explore options for clinical therapies, better coordinate the care a patient needs, and provide telemedicine consultations for follow-up care rather than having the patient travel long distances for these appointments.

The PCC survey also provides a way to measure the effects of VTB services on patient-centered outcomes for veterans in outlying areas who may be especially vulnerable to problems with timeliness and coordination of care. For example, a VA facility that offers VTB services to patients in outlying areas could compare PCC outcomes between those who chose to utilize these services and those who continue to receive usual care, focusing on responses related to coordination of care, care delays, and receipt of timely information.<sup>19</sup> If use of VTB services is found to correspond to higher PCC scores, this would help to demonstrate the value of telemedicine in cancer care from the patient's perspective. Results could also be de-identified and analyzed at the facility/service level to determine whether use of VTB services enhances outcomes related to PCC.

*Using PCC surveillance data to reduce delays in cancer diagnoses.*

An ongoing concern for all types of care providers is missed and delayed cancer diagnosis,<sup>20</sup> which can contribute to poor prognoses for patients and substantial costs to cancer care facilities.<sup>3,21</sup> Among the most important factors contributing to delayed diagnoses are actions taken (or not taken) within individual patient-provider encounters (e.g., adequate history and physical examination, ordering of diagnostic tests and follow-up of abnormal tests or diagnostic information).<sup>2</sup> Although the quality of communication between patients and health care providers has an

important influence on the effectiveness of the encounter,<sup>22</sup> communication outcomes are not routinely measured and tracked.<sup>23</sup>

An ongoing PCC surveillance system could help identify latent, communication-related risk factors that might contribute to delays in cancer diagnosis or subsequent evaluation. As an example, an automated message could prompt veterans to complete the PCC assessment items through MyHealthVet following primary care visits. The scores would be stored in the patient's personal health record and "time stamped" to the date of the visit. Within the EHR, veterans would be tracked for potential delays in cancer-related diagnostic evaluation<sup>24</sup> and alerts could be sent to health care providers if the patient was found to be "falling through the cracks" of the health system.<sup>25</sup> Failure to schedule an appointment and not showing up for appointments or delays in follow-up care could be a function of negative experiences and poor communication as perceived by the patient.<sup>26</sup>

Provided that "high risk" patients (i.e., those with repeated no-shows or otherwise lacking follow-up<sup>27</sup>) have previously used or currently use MyHealthVet, an organizational-level examination of PCC data may provide two sources of information. First, data may reveal low scores on certain items, such as fostering healing relationships ("I felt listened to") and enabling patient self-management (e.g., "I know who to contact and what to do if I have a question or concern when I'm not at the clinic"). If this problem is patient-specific, then steps could be taken to contact the patient and try to reschedule in a tailored way that is caring, respectful, and cognizant of other barriers (e.g., lack of transportation, fear of screening procedure) that interfere with scheduling and keeping appointments. If the problem were found to be more widespread and systemic (e.g., a large number of patient with delays in follow-up care report lower scores in certain PCC domains), this would alert the quality improvement personnel to pursue interventions to evaluate and improve provider-patient communication. For instance, a specific VA cancer unit might score well on all PCC outcomes except on certain items related to enabling patient self-management (e.g., "I got the information I needed on how to take care of myself when I was not at the clinic") and information exchange ("Everyone was on the same page when telling me what I needed to know"). By drilling down into specific problems with cancer patients' communication experiences, a more focused workshop or training could be developed targeting these specific features of effective communication. Indeed, research at the VHA has demonstrated that training physicians on specific communication skills (e.g., agenda setting) can facilitate physician behavior change and improve patients' care

experiences.<sup>28</sup> If similar analyses were performed across VHA facilities, some benchmarking could be possible.

Second, non-response to the PCC assessment surveys, combined with other events such as no-shows, may be an indicator of broader disengagement from VHA health care, especially if patients are using MyHealthVet for other reasons. In such cases, intervention may need to be tailored to a patient's specific needs in order to motivate or help the patient to take a more active role in their health, or it may need to be more systemic if certain types of patients are more disengaged (e.g., minority patients, patients with posttraumatic stress disorder, etc.).<sup>29</sup>

## Conclusion

Ensuring high quality, patient-centered care experiences for all veterans is a top priority for the VHA. Pivotal to achieving this goal is consistent, effective, and patient-centered provider-patient communication. PCC surveillance can inform quality improvement initiatives, the infrastructure for which is well established in the VHA. Appropriate mechanisms must be in place to ensure that PCC is measurable, capable of being implemented broadly, and actionable. As veterans increasingly engage with personal health records to take an active role in their health care, PCC surveillance using MyHealthVet appears to be a feasible approach for monitoring veterans' communication experiences at the VHA. As with any patient survey, the ultimate success of PCC surveillance will hinge on rigorous methods to ensure the highest possible response rates and continuous use of the data for quality improvement.

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## Acknowledgements

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