Measuring Patient Needs to Advance Patient-Centred Care and Reduce Suffering

A new construct enables providers to measure patients' unmet needs and identify opportunities for reducing suffering.

As the industry adopts a more patient-centred paradigm, health care organisations have the opportunity to understand and advance patient centredness through the measurement of unmet patient needs. The goal of advancing patient centredness is consistent with most organisational mission statements and, importantly, with the motivation that brought many clinicians to their present careers.

A new construct enables providers to translate patient data into categories of unmet patient needs in terms previously not addressed through traditional analysis. This approach redefines existing data from the patients' point of view to drive a better care experience, in turn improving patient engagement, clinical outcomes and, ultimately, performance.

The ability to measure unmet needs to advance patient-centred care and reduce suffering is achieved through a novel approach that

- Delineates between suffering "inherent" to the disease and suffering that is "avoidable" in the health care process.
- Categorises these addressable sources of suffering into four actionable areas within the health care organisation: Clinical Excellence, Operational Efficiency, Caring Behaviours and Culture.
- Presents a composite score and provides insight into the unmet needs within each category to address patient suffering and influence overall performance.

Inherent and Avoidable Suffering

The first step in addressing unmet patient needs is recognising that such needs are a reflection of inherent and avoidable sources of suffering that patients endure.

"Inherent" suffering refers to the suffering caused by the disease or event itself– the related pain, symptoms and limitations as well as the fear and worry about how the condition will affect their quality of live and that of their family or friends. Inherent suffering also encompasses the impact of any treatment, even when care is executed flawlessly. Finally the emotional implications of the disease or event—the stress of waiting for a diagnosis and concrete plan, the anxious anticipation prior to tests and procedures, the unavoidable discomfort of certain medical procedures, the navigation through a foreign environment with its own terminology, processes and mores, and the hope for success—are all considered part of inherent suffering.

With the understanding that some pain cannot be eliminated, some procedures will always bring discomfort and some degree of fear and anxiety will always accompany patients' health care journeys, the goal of medicine must be to mitigate inherent suffering to the greatest extent possible, and to accept that acknowledging and alleviating a patient's suffering is part of that healing process.

Conversely, "Avoidable" refers to suffering that arises from dysfunction in the health care system. When patients are not shown courtesy, when their care is poorly coordinated, or when they must wait excessively for an appointment, a diagnosis or an answer, the suffering that they experience as a result is within the control of the health care organisation and completely avoidable.

Distinguishing between inherent versus avoidable sources of suffering sets the stage for an actionable approach to understanding unmet needs.

Measuring Unmet Needs to Advance Patient Centred Care and Reduce Suffering

Current measures of patient experience do not directly ask patients to report their level of suffering. However, they do allow us to understand the extent to which a patient views elements of their care as optimal or not. When patients report sub-optimal care or less-than-perfect experiences, those are opportunities to further reduce their suffering.

Many frequency-based experience of care measures ask patients to report on how often an event occurred while Press Ganey measures ask patients to evaluate the quality of the care.

These measures can be rescaled to represent the distance from optimal fulfillment of patients' needs. Converting Frequency and Press Ganey measures to a single scale that represents the extent to which needs have not been met creates the ability to integrate multiple types of measures and better capture performance in order to address patient suffering.

The Frequency and Press Ganey measures focus on individual attributes of the care experience. Together, they provide insight into the most critical elements that reflect our current understanding of patient needs. By organising these measures into themes, we can identify which patient needs are currently being assessed and what additional areas would be suited for measure development.

The needs described in Table 1 are examples from the inpatient setting. However, the same themes can be applied across different settings. For example, patients have an inherent need for information. Although the need for information may be measured differently in the inpatient setting vs. in a medical practice or home health environment, the need itself is universal to the patient experience.

Table 1. Examples of Needs Currently Being Measured in the Inpatient Setting

Inherent Patient Needs Arising from Disease and Treatment	Patient Needs that Stem from Dysfunction in Care Delivery
■ Pain Control ■ Skilled Care Providers ■ Preparation for Discharge ■ Information ■ Personalisation ■ Empathy ■ Choice ■ Privacy	■ Courteous/Respectful Interactions ■ Reduced Wait Times ■ Comfortable Environment ■ Adequate Amenities ■ Service Recovery ■ Teamwork Among Care Providers

Each of the above needs can be captured and measured using existing standard survey questions. For example, individual items that relate to the need for information can form a composite that captures the extent to which information needs are being met for the patient across the entire experience. Further, we can use relative weight analysis, based on a national study of patient-level data, to determine which questions are more strongly associated with patients' overall perception of care. We can then weight those items accordingly when forming composite measures reflecting a particular need.

For example, in Figure 1, the Need for Information reflects the patient perception of seven distinct survey items. Of the seven, the relative contribution of "Doctor kept you informed" is the largest contributor, followed closely by "How often nurses kept you informed". "Doctors explained things in a way you could understand," "How often nurses explained things in a way you could understand" and "Explanations regarding tests or treatments," are similarly weighted and are next most important. Finally "Staff described new medication side effects" and "Staff told you what new medication was for" have the smallest relative weight of the seven measures.

Figure 1.

Categorising Unmet Needs Into Actionable Areas to Advance Patient Centred Care & Reduce Suffering

Providers must work to reduce patient suffering by identifying and addressing unmet needs. This focus on meeting patients' needs is a marked departure from organising care around specific transactional elements of care within one location or setting, which has historically led to fragmentation and poor coordination.

A new framework for reducing patient suffering called Compassionate Connected Care allows providers to coordinate improvement initiatives across health care settings to address the unmet needs expressed by patients. Within this framework, optimal organisational performance is achieved through the combination of Clinical Excellence, Caring Behaviours, Operational Efficiency and Culture (Figure 2; Dempsey, Wojciechowski, McConville, & Drain).

Figure 2. Compassionate Connected Care

Using the four components of Compassionate Connected Care, organisations can further refine their measurement of patients' unmet needs, and by so doing highlight the types of action that must be taken in order to better meet those needs.

For example, patients' physical needs related to their illness and health promotion are met through Clinical Excellence. Their cognitive and emotional needs are met through Caring Behaviours. Their needs for a streamlined and relatively comfortable health care experience are met through Operational Efficiency. And their need to trust and have confidence in their providers is addressed through Culture.

Figure 3 demonstrates how patient needs can be nested within Compassionate Connected Care components of action. For example, patients' Clinical Excellence needs within the inpatient setting include appropriate pain management, skilled caregivers, and discharge preparation.

Figure 3.

Inherent Needs & Avoidable Suffering	Clinical Excellence	Operational Efficiency
	■ Demonstrate Clinical **Skill** ■ Manage **Pain** ■ Prepare for **Discharge**	■ Minimise **Wait** ■ Provide Clean/Comfortable **Environment** ■ Offer Adequate **Amenities**
	Caring Behaviours	**Culture**
	■ Show **Courtesy** ■ **Inform** ■ **Personalise** Care ■ Show **Empathy** ■ Protect **Privacy** ■ Offer **Choice** ■ Use **Service Recovery**	■ Show **Teamwork**

Understanding the degree to which these needs are met, based on measurement of the relevant survey items, is critical for determining where improvement efforts must be focused. With respect to Clinical Excellence, for example, the relevant patient experience of care items include nurse and doctor skill, how well and how often pain was controlled, the quality of instructions for home care, extent of discharge readiness, discussions around post-discharge resources, consideration of post-discharge preferences, education regarding post-discharge health management responsibilities and medication instructions.

Finally, the metrics from the four components of action—Clinical Excellence, Operational Efficiency, Caring Behaviours and Culture—can be aggregated to form a total composite score that reflects how well an organisation is providing Compassionate Connected Care overall across all these areas. These four components are weighted based on international analysis that determined the extent to which each component drives overall organisational performance.

Addressing patient suffering by measuring unmet needs supports patient-centredness by:

- **Invoking Shared Purpose.** Reducing suffering and meeting patients' needs reinforces the mission of health care organisations, and aligns system values around patient-centred care. This shared purpose facilitates engagement among nurses, doctors and employees. The model changes our understanding of individual measures from mere questions with scores to critical metrics reflecting patient needs and opportunities to better meet those needs.
- **Facilitating Measurement along a Continuum.** First, the model conceptualises individual measures on a continuum from optimal care, where needs are fully met, to where needs are not being met at all, which reflects the largest opportunity to reduce suffering in that area. It emphasises the importance of top box or optimal responses while also preserving the important distinctions between non-optimal responses.

  There is greater opportunity to address suffering if a patient indicates an element of care "Sometimes" happens than if a patient indicates it "Usually" occurs. Similarly, patients who evaluate an element as "Poor" are indicating greater unmet needs than those who evaluate the care as "Good." As a result, this new approach creates a standardised measurement process that allows measures from both Frequency and Press Ganey tools to be integrated into themes of patient needs.
- **Grouping Needs by Patient-Centred Categories.** Once individual measures have been standardised, they can be grouped in a manner that matters to providers. For example, the model includes groupings of items related to information, pain control, courtesy, choice, empathy, etc. These higher order concepts readily promote consensus among clinicians and care providers because they reflect agreed-upon patient needs that matter to both the quality of care and the quality of the experience.
- **Improving the Ability to Understand Met and Unmet Needs.** Once individual metrics are organised into themes based on patient needs, both external and internal benchmarking can be used to better understand gaps in the way care is delivered today for their own patient population. Typically, organisations will benchmark a single item using external comparisons and then craft improvement strategies around improving performance in that single area. Many factors may cause low performance or ranking on a particular item, but a natural reaction from overwhelmed staff is to look for external causes of low performance, such as sicker patients or a more challenging population.

  When categories of needs are benchmarked externally and then compared across an organisation' s performance, care providers can more easily see which needs are currently being met and which patient needs are not. The current patient population and staff performance becomes its own important reference point. There is less of a tendency to categorise the patients as tougher to care for or more difficult to satisfy when it is clear that some of these patients' needs are being met well with the current process and there are just a few specific needs that remain unmet.

For example, an organisation may find that they currently perform well in meeting the needs for pain control, courtesy and empathy, but are not doing as well in areas related to the provision of information and the involvement of patients in choice. Clinicians are also less likely to feel demoralised for not working hard enough, when they see that some elements of the care they are providing are meeting patients' needs. This clears the way for a discussion of actionable ways to modify care processes to meet very specific areas where gaps still exists.

- **Providing Structure for Understanding the Needs of Sub-Populations.** Care providers can better understand the needs of patient subgroups within an organisation by comparing their needs to those of the larger patient population. The identification of unmet needs becomes even richer at the level of clinically similar patients.

  For example, the particular needs of congestive heart failure (CHF) patients or those of coronary artery bypass graft (CABG) patients can be understood relative to the medical and surgical norm, respectively, as shown in Figure 4. These outcomes can then be further explored by expanding each Compassionate Connected Care component, to identify the underlying needs and individual items associated with them. In this way, particularly low performing areas can be better understood and areas that appear average on the surface but represent a mixture of met and unmet needs can be discovered, as shown in Figures 5 and 6.

Figure 4.

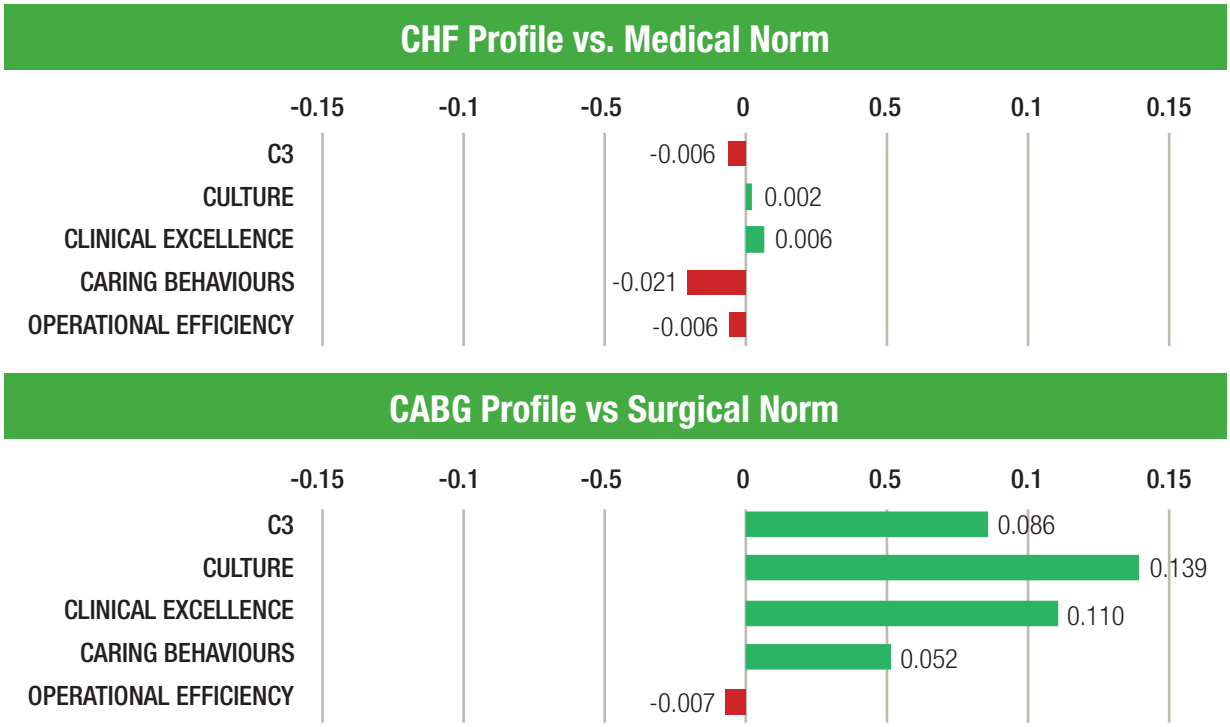


Figure 5 provides an example of organisational performance by the four key dimensions—Clinical, Operational, Caring and Cultural—for CHF patients within a sample health system. This example indicates below-average performance related to the needs of CHF patients within Caring Behaviours, suggesting the needs of CHF patients around such things as being kept informed, privacy, personalised care, courtesy, empathy, choice and service recovery are being less fully met than those of the average medically treated patient.

At the item level, specific performance on individual questions provides insight into where improvement efforts should be focused. The "Inform" need is the lowest-performing need across the profile for CHF patients, indicating these patients report their need for information is less well met than other medically treated patients. Moving to the individual measure level, the greatest opportunity to improve performance is by better explaining to CHF patients the purpose of new medication. There are also significant opportunities for doctors and nurses to explain things in a way that patients can understand.

In the same example, organisational performance on the "Discharge Preparation" measure suggests the needs of CHF patients around discharge are being met better than those of the average medically treated patient. However, at the item level, there is a disparity between the "check-the-box" elements of discharge, such as providing information in writing about the symptoms to look out for, and the more complex discharge prep issues that address patients' preferences around discharge planning and helping patients understand how to manage their health after discharge. This could explain why CHF patients indicate feeling less well prepared for discharge than other medically treated patients.

The chronic, progressive, and often unpredictable nature of CHF creates different needs for information among these patients. Awareness of these needs can guide clinicians in their communication efforts to help patients better understand their condition and the care plan.

Similar insight can be gleaned from the CABG example in Figure 6. Overall, the "Inform" measure appears to be above average, but the item-level view shows disparities across the different elements of information exchange. Patients indicate some opportunity to improve the extent to which doctors explain things in understandable language, and an even greater opportunity to provide information about the purpose and possible side effects of new medications.

The lowest-performing need across the profile for CABG patients is Environment. At the individual measure level, the largest opportunities to better meet these patients' environmental needs center on reducing the noise level and addressing issues related to room temperature. Post-surgical monitoring for patients having CABG surgery requires multiple checks during the night. Disrupted sleep makes one more likely to notice the sounds of the hospital environment at night- and those sounds in turn, make it difficult to return to sleep. With this in mind, working to create a quieter, more healing environment should go hand-in-hand with helping CABG patients understand why they will be woken throughout the night.

Figure 5. Segmentation of Organisational Performance by Medical Condition: Congestive Heart Failure (CHF)

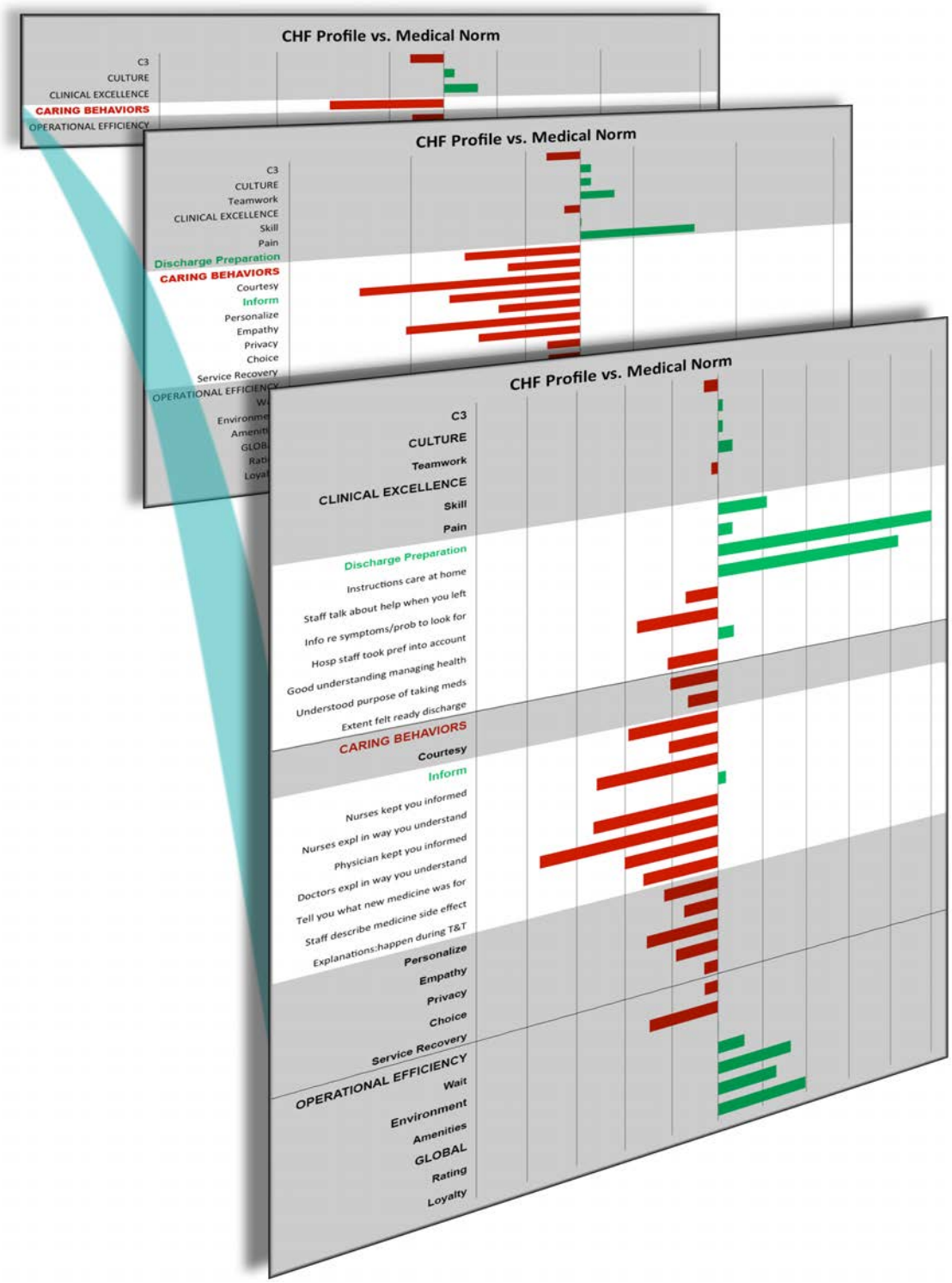
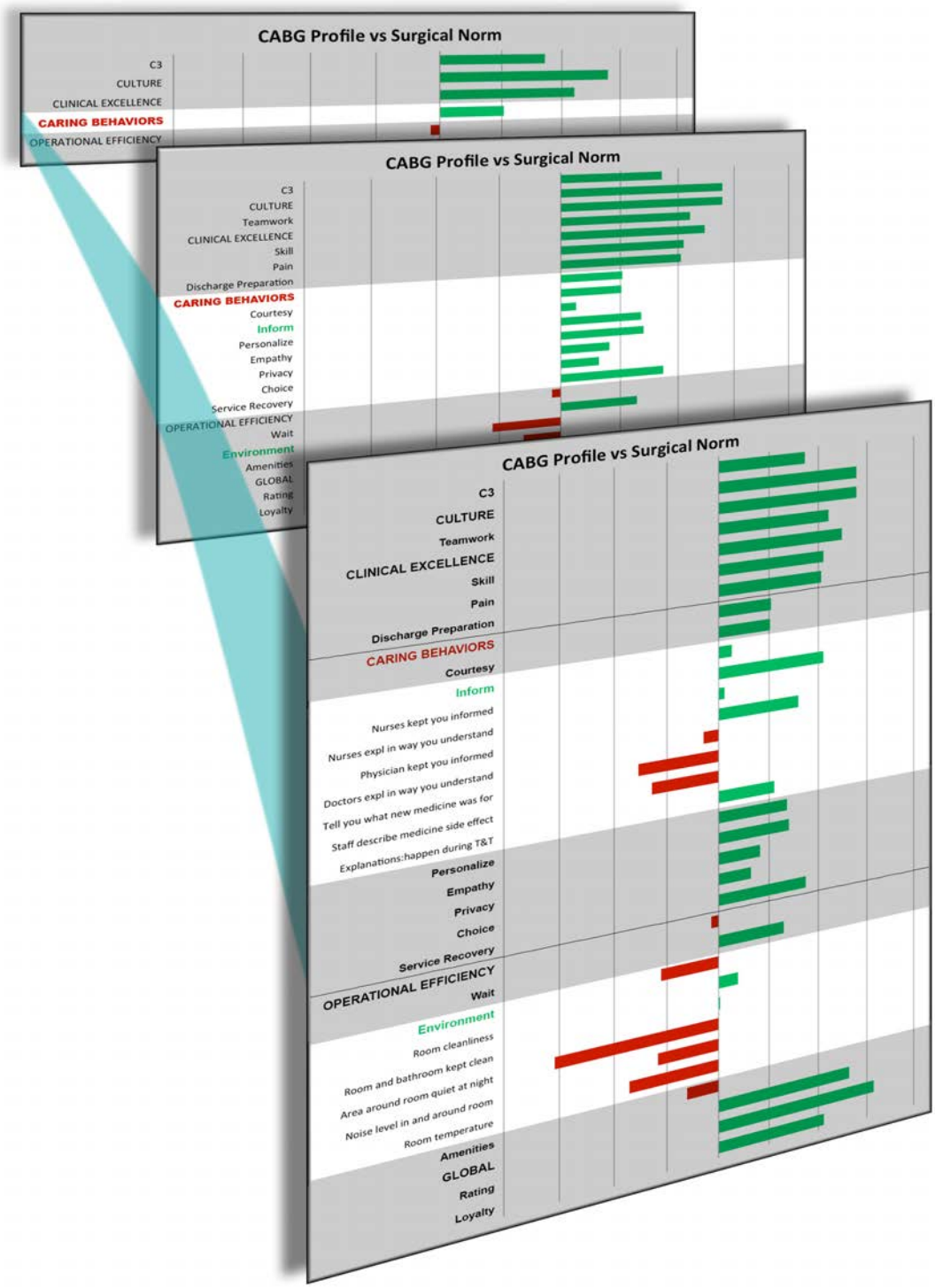


Figure 6. Segmentation of Organisational Performance by Surgical Condition: Coronary Artery Bypass Graft (CABG)



- **Shifting the Mindset from More Care to Different Care.** Philosophically, focusing on reducing suffering places emphasis on removing barriers to a positive state rather than layering additional strategies on top of sub-optimal care. By focusing on understanding and responding to unmet needs, the conversation changes from one that assumes low scores equals low staff performance into one that suggests we have to do something different to meet patients' needs. Shifting the focus to care redesign moves organisations beyond short-term fixes to improving the quality of care.
- **Creating a Structure for Action.** This new framework offers a novel way to think about patient feedback and evaluations of care. It provides a strategic approach to respond to patient needs and reduce suffering. It also provides a way to organise action to respond to the identified opportunities. Successful organisations must leverage and integrate Culture, Clinical Excellence, Operational Efficiency and Caring Behaviours to provide reliable and optimal care. This framework directly ties unmet patient needs to the components of care needed to take action for improvement.

The Right Approach for Health Care

Patients suffer—both physically and emotionally—and sometimes that suffering is caused by the dysfunction of the health care delivery system. We must acknowledge and respond to their suffering as part of our efforts to treat and heal, and we need to be cognizant of opportunities to prevent additional, unnecessary suffering.

A critical strategy for creating value is measuring what matters to patients, identifying unmet needs that contribute to suffering and systematically improving performance to better meet those needs. In today's complex and pressured health care environment, organisations that succeed in driving improvement in this way will also succeed in attracting and retaining a population of patients to serve. Focusing efforts on responding to patient suffering by meeting patients' needs is a differentiating strategy that creates value for patients, re-engages those who provide care in the mission of health care and supports an engaged workforce of clinicians.

Reference

Dempsey, C., Wojciechowski, S., McConville, E., & Drain, M. (2014). Reducing patient suffering through Compassionate Connected Care. *Journal of Nursing Administration,* 44(10), 517-524

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