

**Measuring What Matters Most: Whole Person Outcomes & Well Being**

State of the Art Conference

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**Summary Points and Considerations for Next Steps**

The motivation for this conference: **We propose that better measures of whole person outcomes could redirect VA’s focus to align with patients and incentivize different actions.**

We measure what outcomes we think are important. Yet, individual disease-specific measures don’t capture what patients’ value. Current measures often focus on narrow health measures instead of broader aspects of well-being, such as reducing anxiety over food, housing, or financial insecurity. VA has programs and services that address these broader aspects of well-being, but we are not currently routinely capturing information on the impact those have on Veterans’ lives.

This State-of-the-Art Conference (SOTA) has identified the first steps towards this vision of better measures of whole person outcomes by thinking about what is important to patients.

1. **Begin with voice of the Veteran.** There was a clear consensus among each of the three SOTA work groups to start with what is important to Veterans. There is an immediate need for a process to engage a large and diverse group of Veterans about what they think we should be asking about whole health status.What matters to them? What do Veterans think well-being is? Is the next step a conference or series of focus groups? We don’t want to reinvent the wheel. We need to work together (Veterans Experience Office (VEO), VBA, VHA, etc.) and engage the Social Determinants of Health Integrated Project Team (SDOH IPT) and Well-being IPT. We also need to leverage Veteran Engagement groups developed by the HSR&D COINS, if we have questions to ask. Consider:

* **User-centered Design is essential**. **VEO has a process about whether to survey or use focus groups** [also have a research exemption]. VEO could do a journey map.
* **Access people who aren’t highly engaged already and don’t use VA care.** Who are these populations and how do we get access to include them?
* Tap into the Veteran experience to understand what they think they need to get to the next level. Measure their capacity (patient activation) and where they are in their journey. What is their knowledge of what skills they need [in managing health, conditions, SDOH].

2. **Define the nomenclature.** Develop a framework or logic model to structure a conversation on measures. What is the whole person framework and is there a possible composite measure?

* What Domains, Measures, Indexes should be within this Framework? We need domain specific measures. We need to decide whether to aggregate into an index.
* Incorporate existing frameworks and measures where we can. Need to start with what’s there, think about ability to integrate existing measures in framework, particularly those that come with a cost.
* Need more work on how “whole health” and “wellbeing” is defined. Differing opinions on whether some aspects of health are components of well-being, or whether aspects of health are components of whole health (as in NIH model) along with well-being.
* Academic literature on wellbeing is highly developed, but there is less research on how to study this in a healthcare setting.
  + - * 1. Health and Wellbeing overlap
        2. Take wellbeing out of the whole person health model being developed at NCCIH?
        3. Say well-being is within Whole Health? Some other way to solve the problem?
* Consider the terminology: Whole Veteran vs. Whole Person.
* Initial Steps need a priority goal about well-being because it is used in the Strategic Plan.
* **Many factors outside healthcare influence wellbeing, and the care system should be aware of these factors**. What to focus on? Only those that VA can influence?
* The value of **well-being** is not only as an outcome, but **as a moderator or mediator** – maybe underlying well-being influences how effective certain interventions are in treating disease.
* **Social determinants** **are an important part of wellbeing** (e.g., social isolation).
  + Are they primarily a mediator of well-being or an outcome -component (domain)?
    - SDOH IPT can review this (Reena Duseja, cochair)
  + What SDOH get incorporated and how?
* Need to address **spirituality**, **connectedness**, **life purpose** concepts and needs more data.

1. **We need a process to come to consensus on what framework to use**. This might be informed by what data are readily available but shouldn’t be driven solely by that.

* The Well Being IPT may influence this process.
* We should **work with** **the** **IPTs to** **create an inventory of existing data** that could contribute to this composite set of measures. Also, think about what is missing (e.g., measure of isolation or social connectedness). What is the process of mapping inventory against domains? Example of NIH toolbox to show how contract mechanisms can produce a useful tool.
* Refer to the National Quality Forum for proper terminology on measurement. Process, outcomes, structure, composite.
* Need to include developers with measurement expertise because there is a science to doing measure development.
* Difference in use of word **measure vs. tool**. “Measure” has an attribution about whether it was done and by whom. “Tool” is more about how well something was done. Use of these terms vary across disciplines. VA terms things differently. “Metric” within VA is different from a measure.
* **Give thought to Use Case** for each element and domain. A category will not work unless it can be implemented in an unencumbered and unbiased way. CMS wants to support this. **Include mental, as well as physical, health in these frameworks.**

1. We need to think carefully of the **audience for this information** (clinicians vs. policy makers vs. researchers) and how it will be used (user centered design).

* Deciding who the audience is, may affect the choice of measures. Is the goal to:
  1. track movement at a population level (in which case you want items that are responsive to change); or to
  2. identify status of patient (wherein some non-responsive measures like environment may be useful)?
* Danger in driving wellbeing down to an accountability measure, but as an organization we want to know how well are doing in serving the population. Clinicians and care teams should be aware of the population measure but working towards a metric they can achieve.

1. Where do **caregivers** get brought into this? Only through relationship with patient or in another way? Consider their interaction with the health care team.
2. **For** **use in clinical care, we need to** **test**:
   1. How do we collect measures (task or research question)?
   2. How do we present them?
   3. How do we implement them in a stressed system? Maybe take something away?
      1. Also need voice of provider to make sure they work
   4. If we can collect, present, and implement, **can we show that it leads to better outcomes?**
3. **How would we advance this work?** 
   1. Perhaps an HSR&D nationwide Consortia of Research (CORE) could lead a workgroup, identify data sources, connect to operations partners, and run rapid pilots? Would need budget for this.
   2. Perhaps have REiR person to help with this, or have external team do focus groups?

**Next Steps**

1. Planning Committee meeting (post-Conference)
2. Journal supplement in a special issue of Medical Care. A Call for Papers will follow.
3. Informational Briefing to SECVA call: update on progress and wellbeing measurement
4. Cyberseminar on overarching themes and takeaways
5. Alert and continue engaging other interested parties (Wellbeing IPT, SDOH IPT, VBA, VHA, VEO, NIH, other agencies, measurement organizations, GROVE, VSOs)
6. Process to come to consensus on a framework (involving Veterans and clinicians)
7. Identify research and other capacity to support the process