COMMON QUESTIONS TO BETTER SERVE OUR VETS

Common Data Elements for Veteran-serving Nonprofit Organizations:

Practice Recommendations from the George W. Bush Institute's Warrior Wellness Alliance

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WARRIOR WELLNESS ALLIANCE
GEORGE W. BUSH INSTITUTE

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About the George W. Bush Institute:

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About the Warrior Wellness Alliance:

The Bush Institute's Military Service Initiative helps post-9/11 veterans and their families make successful transitions to civilian life with a focus on optimizing health and well-being and leveraging meaningful education and employment opportunities. Its Warrior Wellness Alliance links peer-to-peer veteran networks to connect more veterans to effective clinical care. By increasing understanding of the invisible wounds, improving the delivery of care, and advocating for more effective treatment, the Warrior Wellness Alliance aims to increase the number of veterans receiving high-quality care for the invisible wounds of war — when and where they need it.

Warrior Wellness Alliance Members:

George W. Bush Institute

The Mission Continues

Wounded Warrior Project

Student Veterans of America

Team Rubicon

Team RWB

Cohen Veterans Network

Marcus Institute for Brain Health

SHARE Military Initiative at Shepherd Center

Travis Manion Foundation

U.S. Department of Veterans Affairs/Veterans Health Administration

WWP Warrior Care Network: Emory Healthcare, Massachusetts General Hospital, Rush University Medical Center, and UCLA Health

To learn more, visit www.BushCenter.org/wwa.

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INTRODUCTION

The George W. Bush Institute's Warrior Wellness Alliance (WWA) aims to connect more veterans who experience the invisible wounds of war to high-quality healthcare providers when they need them. This is accomplished by linking peer organizations that serve post-9/11 veterans and effective clinical healthcare programs across the country. At its inception in 2017, the WWA was comprised of six 501(c)(3) nonprofit organizations (Bush Institute's Team 43; Student Veterans of America; Team Red, White & Blue; Team Rubicon; The Mission Continues; and Wounded Warrior Project), which we refer to as "peer-network organizations" because of the veteran peer-to-peer connections they assist veterans in making through their programs. For many of the WWA peer-network partners, connections extend to family members, civilians, and the broader community. The WWA also includes eight clinical providers (Cohen Veterans Network, Emory Healthcare Veterans Program, Massachusetts General Hospital's Home Base Veteran and Family Care, Marcus Institute for Brain Health, UCLA Health's Operation Mend, Rush University's Road Home Program, Shepherd Center's SHARE Military Initiative, and the Veterans Health Administration).

As the WWA was carrying out its foundational work, it became clear that in order to connect more veterans to quality care when they needed it, we needed more informative data on the veterans being served by WWA partners. The WWA prioritized this work for the following reasons: 1) to help the WWA better understand which veteran "customers" were engaged in our collective Alliance organizations, 2) to understand which veteran groups were not being served through Alliance organizations, and 3) to optimize available WWA data in order to more strategically and effectively develop programs to meet the well-being needs of post-9/11 veterans. To that end, in 2019, the WWA created a work group devoted to understanding and optimizing the data being collected about veterans who are engaged in the WWA peer-network organizations to develop common data elements (CDEs).

What are Common Data Elements (CDEs)?

Common data elements are standardized variables that are collected and stored uniformly across research or organizations to enhance data quality, sharing, and comparisons over time[1].

A CDE is uniform in four ways:

- consistent naming of the questions (i.e., "items");
- the wording of the actual survey item;
- the available response choices that can be selected as an "answer"; and
- the formatting of the responses for analysis and data exchange[2].

WWA COMMON DATA ELEMENTS DEVELOPMENT PROCESS

The WWA CDE work group analyzed operational information shared by the WWA peer-network member organizations in order to develop a list of recommendations and CDEs to be adopted across the WWA. Through interviews and supporting documentation, all peer-network member organizations shared information that included: data-collection practices, questions asked to new members during organization onboarding, evaluation methods (e.g., pre-post surveys distributed), and other data collected by WWA peer-network organizations on participating members. Using this information, a single list of all variables collected was developed and then categorized by the type of information and the timing within the organization in which the information was collected. This list was then analyzed by clinical and reintegration stress experts, who were asked to identify the most value-added 15 variables that could be considered CDEs that were not clinical-assessment measures.

We aimed to identify CDEs that allowed each organization to maintain true to its individual organization's mission and business processes. Early in the process, we determined that integrating clinical or psychological assessment measures would likely be a step too far. Therefore, we focused our recommendations on CDEs that could be considered for broad adoption across all nonprofit veteran service organizations (VSOs). We also set the maximum number of recommended CDEs at 15. This would allow the CDE work group to leverage variables already consistently and widely used by WWA peer-network organizations for operational purposes, yet not be too burdensome for VSOs to implement. We envisioned that the CDE variables would potentially become smaller components of an organizations' larger data-collection efforts, recognizing that adoption of the CDEs may in some circumstances only be organizationally viable if they can be integrated into business practice as usual.

Therefore, we recommended CDEs based upon how the variables might inform:

- Comparisons to other populations of veterans for representativeness (i.e., U.S. Census data, Millennium Cohort Study, National Health Study for a New Generation of U.S. Veterans, etc.);
- Clinical-treatment planning should organizations be able to individually identify a member based upon survey responses and refer them directly to care; and
- Organizational practice of designing and implementing new programs to address previously unidentified health-and-wellness educational and programmatic needs.

Findings from the CDE work group discovery efforts indicated that overall peer-network organizations recorded data at three points-in-time, which varied by organization. Those data-collection periods encompassed:

1. initial information at new member sign-up
2. pre- and/or post- program participation surveys and
3. an annual, anonymous membership-wide survey.

Following the data cataloging and discussion between WWA CDE work group members, recommended variables were corroborated with the academic and clinical literature.

15 items were generated as common data elements. The final 15 CDEs were characterized under three broad categories:

1. general demographics
2. military-specific demographic information, and
3. veteran well-being.

CDE item wording was based upon validated instruments, review of the relevant academic literature, expert guidance, and WWA peer-network member organizations' current practices, especially if consistency was already established across organizations as to how a particular question and its response option were formatted. We sought to minimize any potential burden that might impede WWA peer-network member partners' adopting the CDEs, particularly in regard to question-and-response formatting of general demographic and military-specific variables. Our default was to recommend the most comprehensive response options consistent with our consulted resources and those already in place by at least one organization. Items were field-tested by 39 veteran members participating in two of the WWA peer-network organizations to assess for ambiguous, difficult, or sensitive questions; since 55 veterans were emailed at the outset, it reflects a 71% response rate. While eight participants responded that at least one question made them uncomfortable, no single item was endorsed frequently enough (more than twice) to be deemed "too sensitive" and was subsequently removed as a CDE question-or-response option. Based upon the field test feedback, four slight modifications were made to the CDEs to provide more descriptive information and inclusive response options. Additional methodological detail and response options, plus coding is available in Appendices A and B.

KEY RECOMMENDATIONS AND FIFTEEN COMMON DATA ELEMENTS

The recommendations included in this section represent the categories of common data elements; full descriptions of each common data element, as well as question-and-response options are included in Appendix B.

Recommendation 1: Collect general demographic and military-specific demographic variables when new members sign-up.

Organizations should keep intake questions for new members enrolling in a VSO as short as possible to reduce participants' question burden and fatigue (which may deter completing member sign-up), while still getting the information that provides insight into the representativeness of the member population.

At organizational intake, we propose that the following *general demographic* and *military-specific demographic* variables be collected and stored on new member records (if appropriate). Nearly all of these variables have been previously recommended and adopted as CDEs for psychological health and traumatic brain injury clinical and research studies[3,4,5,6] or have appeared in a WWA peer-network organization's existing survey[7]: *general demographics (gender[8,9], age, race/ethnicity, and productive activity)* and *military-specific demographic variables (military branch of service, with or without combat exposure; length of military service; military rank; and service-connected chronic condition[7,10])*.

General Demographics

- Gender
- Age
- Race/Ethnicity
- Productive Activity

Military-Specific Demographics

- Branch of Service, Combat Exposure
- Length of Military Service
- Military Rank
- Service-Connected Injury or Illness

Recommendation 2: Collect additional demographic variables, marital status, and sexual orientation at a second data-collection point.

For organizations that maintain ongoing individual member records with identifiable personal data, we recommend the following two additional general demographic variables be collected, in addition to the general demographics and the military-specific demographics collected at new member sign-up. These variables may be assessed at another routine data-collection point within the organizations' standard data-collection practices (such as pre-/post-program participation): *marital status[7] and sexual orientation[8,9]*. While we believe that these two general demographic data variables (*marital status and sexual orientation*) are essential CDEs for better understanding our members, we do not necessarily recommend that they be collected at the initial sign-up in order to reduce onboarding question burden. We encourage organizations to determine whether these variables are appropriate to retain on their identifiable member records.

General Demographics

- Marital Status
- Sexual Orientation

Recommendation 3: Collect well-being variables (thriving, substance usage, firearm access/storage practices, potential reintegration stressors, and perceived unmet health needs) at an anonymous assessment point.

For organizations conducting anonymous annual surveys and reporting information in aggregate form (de-identified to individuals), we recommend the following variables be collected: *thriving*[7,11,12,13,14,15], *substance usage*[7,16], *firearm access/storage practices*[17], *potential reintegration stressors*[7,18,19,20,21,22,23,24,25], and *perceived unmet health needs*[26]. These variables will help organizations understand the peer-network membership base (and potential programmatic needs) as a whole. We define thriving as positive social relationships; physical, mental, and spiritual health; fulfilled material needs; a sense of purpose; positive role identity; positive emotion; resilience; and continued community engagement and service to others[11,27,28,29]. The variables on firearm access/storage practices and on adverse childhood experiences were the only variables included in the CDEs that were not collected by any of the WWA peer-network organizations in existing practices. They were included because of their importance as risk factors for potential reintegration stress issues or adverse health outcomes. Because components of well-being (particularly firearm access/storage practices, mental and brain health-related questions, and marijuana/drug use questions) most frequently appeared in field test feedback from veteran respondents as potentially sensitive questions, we recommend anonymous data-collection of these items. We understand organizations may wish to collect this information as personally identifiable data. As with all data-collection practices, we highly encourage organizations to consider including a statement to respondents as to how the information will be utilized by the organization and who will have data access.

The Warrior Wellness Alliance defines **thriving** as positive social relationships; physical, mental, and spiritual health; fulfilled material needs; a sense of purpose; positive role identity; positive emotion; resilience; and continued community engagement and service to others.

Additionally, if organizations utilize clinical screening tools, we strongly encourage the use of valid and reliable instruments for data-collection. However, we recommend that organizations do not collect data that could indicate a potential clinical treatment need *and* is individually identifiable *unless* there is the capacity and process in place to refer the individual for further assessment by a licensed, clinical health care provider.

Well-Being Measures
(anonymous data-collection)

- Thriving
- Substance Use
- Firearm Access/Storage Practices
- Potential Reintegration Stressors
- Perceived Unmet Health Needs

WHY IS THIS WORK SO IMPORTANT?

To effectively and efficiently serve veterans, it is critical to understand who they are and what they may need. Our recommendations add value to individual WWA member organizations, as well as to key stakeholders and other organizations looking to know and serve post-9/11 veterans better for the following reasons:

For WWA Peer-Network Members and the Broader VSO Community:

- **To better understand the strengths and challenges of the veteran population** they are serving, thereby increasing opportunities to identify potential gaps for programming related to member well-being.
- **To empower organizations to use their membership data to articulate the organization's public health impact** (as a secondary or tertiary mission) beyond the primary mission to key stakeholders, partners, funders, etc. Since conversations about the health of veterans are occurring across multiple sectors, organizations that can articulate how their own membership base is affected by the highlighted health issues are better positioned to communicate to other leaders on their members' behalves.
- **To highlight attributes of veteran well-being that focus on thriving** in addition to other potential health-influencing factors (such as potential reintegration stressors), thereby providing a holistic view of veteran wellness.
- **To generate a comparative data set based upon the utilization of the 15 CDEs** that VSOs, funders, academic researchers, and clinicians can use as a point of comparison for overall veteran population health.

We also see value for the clinical and research-based communities for the following reasons:

- **To understand estimates of the WWA peer-network veterans' and broader VSO communities' demographic and health profiles** to help identify potential needs and gaps in services not already in focus.

We recommend that peer-network members with annual anonymous surveys include a direct question to members asking them about their unmet mental and physical health treatment needs and referring those who respond affirmatively to the WWA resource page.

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We propose that organizations looking to accomplish the goal of referring more veterans to effective treatment explore opportunities to create an integrated assessment and referral process as part of day-to-day organizational practice and/or through partnerships with experts.

- **To reduce the number of times a veteran is asked personal demographic- and/or health-related questions.** Organizations with established referral processes and an individual's consent will be able to facilitate a "warm handover" of a veteran in need to a clinical partner by sharing information that has already been collected and stored on the member's organizational records with the clinical partner. Doing so reduces the redundancy in data-collection and burden on the veteran member to provide information to partner organizations that are already collaborating.
- **To provide data-driven opportunities for WWA partners** to potentially offer clinical guidance to peer-network organizations for the development and implementation of public health programming aligned with peer-network member organizations' and veteran service organizations' member base and mission.

NEXT STEPS

The WWA CDE initiative is a significant step forward to standardizing data-collection activities across VSOs. Consistent with the development of CDEs for healthcare operations and research[4,5], the 15 WWA CDEs are the first CDE recommendations for nonprofit veteran service organizations. They represent a balance of variables focused on veteran well-being, to include thriving and potential reintegration stressors, while aiming for brevity and low burden on the respondent.

The recommended 15 CDEs are not intended to be an exhaustive list of the only items VSOs should collect on their members. Rather, they are intended to reflect a variety of variables already (albeit inconsistently) being collected by WWA peer-network member organizations overlaid with key elements relevant to reintegration stressors, risk factors associated with the invisible wounds of war, and thriving. The list creates a starting point of potential questions to include in membership-wide individually identifiable and anonymous assessments of program participants. At a minimum, we see significant value in implementing consistent item wording across organizations to holistically assess veteran well-being beyond what is currently recorded to inform dialogue, programming, clinical treatment planning, research opportunities, and most importantly, serve veterans better.

All participating WWA peer-network organizations have committed to the adoption of the CDEs to the extent feasible in 2020; meaning, all member organizations indicated they intend to adopt the 15 items in the next wave of data-collection efforts. And, all have committed to working towards them in the future as part of their leadership in the WWA. Finally, the WWA encourages all veteran-serving organizations to implement the CDEs, and we will continue to monitor and track adoption efforts, refine the set of common questions, and provide updates to the community as our knowledge about needs within the veteran community develops.

APPENDIX A

The George W. Bush Institute Military Service Initiative (GWBI) spearheaded the CDE initiative as one of three WWA priorities of effort to connect more veterans to effective care for the invisible wounds when they need it. In 2019, the WWA systematically cataloged the variety of questions being asked by WWA peer-network organization members and the points in organizational practice where they were being administered. Our goal was to create a small-item bank of operationally useful and clinically insightful CDEs for use by organizations serving the military service-connected community. This effort is aligned to one undertaken a decade ago by federal agencies establishing common data elements for psychological health and traumatic brain injury studies.

The George W. Bush Presidential Center convenes WWA in-person meetings biannually at which typically two members from each WWA organization attend. Ongoing work between in-person meetings is conducted through email and monthly video conference calls. WWA CDE work group participants self-selected into the CDE work group based upon their expertise and interest in the subject matter. Throughout the course of developing the CDEs, four members of the GWBI team, five members from WWA peer-network organizations, and five members from WWA clinical partners participated in ongoing discussion and refinement of the CDEs, with a group discussion of all WWA members from the 13 organizations in attendance at the April 2019 WWA meeting providing feedback. Occasionally, subject matter experts outside of WWA members were consulted to increase our understanding of best practices to inform recommended items. One-to-one video conferences were also held between GWBI work group members and senior leaders from each peer-network organization. Backgrounds of participating work group members included social work, behavioral health, psychology, law, psychiatry, nursing, public health, and nonprofit executive-level leadership. Final recommendations and CDEs were drafted by GWBI work group members and circulated to the WWA for discussion and feedback.

APPENDIX B

FIFTEEN COMMON DATA ELEMENTS WITH CODING

General Demographic Common Data Elements Collected at New Member Sign-Up

Gender

1. Do you think of yourself as (please select one from):

(1) Man
(2) Woman
(3) Transgender man
(4) Transgender woman
(5) Nonbinary/gender fluid
(6) Other (text write-in)
(7) Prefer not to answer

Age

2. Date of Birth:

Calendar Selector for Month/Day/Year

	Month	Day	Year
Please Select: (1)	▼ January (1 ... December (12)	▼ 1 (1 ... 31 (31)	▼ 1900 (1 ... 2049 (150)

Age can be calculated from Date of Birth by subtracting the birth date from the current date.

Race/Ethnicity

3. Please select one or more of the following which you feel best describes you:

(1) American Indian or Alaska Native
(2) Asian or Asian American
(3) Black or African American
(4) Hispanic, Latino, or Spanish Origin
(5) Native Hawaiian or other Pacific Islander
(6) White or Caucasian
(7) Other, please specify _____

Productive Activity

4. Which of the following categories best describes your situation in the last 6 months? Please select all that apply.

(1) Employed, working full-time
(2) Employed, working part-time
(3) Not employed, looking for work
(4) Not employed, not looking for work
(5) Retired
(6) Full-time student
(7) Part-time student
(8) A combination of work and school
(9) Disabled, not able to work
(10) Home duties
(11) Other, please specify

Military-Specific Demographic Common Data Elements Collected at New Member Sign-Up

Military Branch of Service, with Combat Exposure

5. In which branch (or branches) of the United States military have you served? Please also select the **bolded** choice if you have served in a combat or war zone.

(1) Air Force
(2) Air Force Reserve
(3) Air Force National Guard
(4) Army
(5) Army Reserve
(6) Army National Guard
(7) Coast Guard
(8) Coast Guard Reserve
(9) Marine Corps
(10) Marine Corps Reserve
(11) Navy
(12) Navy Reserve
(13) Foreign Allied Military
(14) **Served in a Combat or War Zone**

Length of Military Service

6. Please provide year entered into military service and year completely separated from military service.

Calendar Selector for Year

	Year
Year Entered Military Service (1)	▼ 1900 (1 ... 2049 (150)
Year Completely Separated from Military Service (2)	▼ 1900 (1 ... 2049 (150)

Military Rank

7. What is the highest military rank you obtained?

(1) E1
(2) E2
(3) E3
(4) E4
(5) E5
(6) E6
(7) E7
(8) E8
(9) E9
(10) E10
(11) O1
(12) O2
(13) O3
(14) O4
(15) O5
(16) O6
(17) O7
(18) O8
(19) O9
(20) O10
(21) W1
(22) W2
(23) W3
(24) W4
(25) W5

Service-Connected Chronic Condition (Injury or Illness)

8. Do you have a service-connected chronic condition (i.e., injury or illness)? If so, please select the choice which applies to you.

(1) I do not have a service-connected chronic condition
(2) I have a service-connected chronic condition, but did not submit a claim to the VA.
(3) I am in process of submitting a claim.
(4) Claim submitted, waiting for a VA decision
(5) Appealing current decision
(6) Unsure
(7) 0% VA Disability Rating
(8) 10% VA Disability Rating
(9) 20% VA Disability Rating
(10) 30% VA Disability Rating
(11) 40% VA Disability Rating
(12) 50% VA Disability Rating
(13) 60% VA Disability Rating
(14) 70% VA Disability Rating
(15) 80% VA Disability Rating
(16) 90% VA Disability Rating
(17) 100% VA Disability Rating
(18) Does not apply to me

General Demographic Common Data Elements Collected at Secondary Data-collection Point

Martial Status

9. Which of the following best describes your current relationship status?

(1) Single, never married
(2) Single, but cohabiting with a significant other
(3) Married
(4) In a domestic partnership or civil union
(5) Separated
(6) Divorced
(7) Widowed

Sexual Orientation

10. Do you think of yourself as

(1) Lesbian/gay/homosexual
(2) Bisexual
(3) Straight/heterosexual
(4) Something else
(5) Prefer not to answer

Well-Being Common Data Elements Collected at Anonymous Data-Collection Point

Thriving

11. Please select all of the following which apply to you

(1) My physical health is good, very good, or excellent.
(2) My mental health is good, very good, or excellent.
(3) My spiritual health is good, very good, or excellent.
(4) I have a sense of purpose (goals and direction) in my life.
(5) I feel part of something bigger than myself.
(6) I have a positive impact on my community through volunteering and/or leading others.
(7) My role in my family, work, or community is a positive source of self-worth and connection to others.
(8) Most days my outlook is positive (optimistic, grateful, proud, energized, hopeful).
(9) I have people to turn to for information, resources, and emotional support.
(10) I feel loved.
(11) Over the course of one week, I do at least 2.5 hours of moderate-intensity exercise (i.e., brisk walking or general building tasks like roofing, painting, etc.) or 1 hour 15 minutes of vigorous activity (i.e., running or heavy shoveling, moving heavy loads, etc.).
(12) I tend to bounce back quickly after hard times.
(13) I am able to meet normal monthly living expenses without worry.
(14) None of the above.
(15) Prefer not to answer.

Substance Usage

12. In the past year, how many times have you used the following?

	Never (1)	Once or Twice (2)	Monthly (3)	Weekly (4)	Daily or Almost Daily (5)
Alcohol ○ For men, 5 or more drinks a day ○ For women, 4 or more drinks a day					
Tobacco Products					
Prescription Drugs for Nonmedical Reasons					
Ilegal Drugs (non-Marijuana)					
Marijuana, ***for medical reasons*** (cite any use: smoking, eating, drinking, vaporizing, or dabbing of all forms of the plant, including CBD)					
Marijuana, ***for recreational reasons*** (cite any use: smoking, eating, drinking, vaporizing, or dabbing of all forms of the plant, including CBD)					

Firearm Access/Storage Practices

13. Please select the choice that fits best regarding your access to firearms.

(1) Firearms are not kept in or around my household.
(2) One or more firearms are kept in or around my household, and all of them are stored locked and unloaded.
(3) One or more firearms are kept in or around my household, and one or more of them are not stored locked and unloaded.
(4) Prefer not to answer.

Potential Reintegration Stressors

14. Please select all of the following which apply to you. We realize that this is sensitive information, but it will help us to understand the challenges veterans in our community are facing. None of your responses will be associated with your name.*

(1) "Other than honorable," "bad conduct," or "dishonorable" discharge.
(2) History of having EVER been diagnosed/treated for a traumatic brain injury.
(3) Currently having trouble falling asleep, experiencing sleep that is restless or disturbed, or awakening early in morning.
(4) Current post-traumatic stress symptoms.
(5) Current mental health condition not diagnosed as post-traumatic stress (such as depression, anxiety, etc.).
(6) Currently feeling lonely, left out, isolated, or lacking companionship.
(7) History of military sexual trauma.
(8) History of one or more adverse childhood experiences (psychological, physical, or sexual abuse; violence against mother; parental separation or divorce; or living with household members who were substance abusers, mentally ill or suicidal, or ever imprisoned.
(9) History of having ever been detained or under the supervision of the criminal justice system through arrest, court involvement, or imprisonment.
(10) In the last 24 months, you had concerns about losing secure housing (couch surfing is not secure housing).
(11) None of the above.
(12) Prefer not to answer.

***IMPORTANT SURVEY-DESIGN NOTE:** Please remove the statement "None of your responses will be associated with your name," if responses will be linked to individually identifiable information.

Perceived Unmet Health Needs

15. Was there any time in the past 12 months when you thought you needed treatment or counseling for mental health issues or physical health concerns but did not receive services? Please select all that apply.

(1) No
(2) Yes, mental health
(3) Yes, physical health
(4) I am currently receiving mental health services.
(5) I am currently receiving physical health services.
(6) Prefer not to answer.

***IMPORTANT SURVEY-DESIGN NOTE:** Those who select "Yes, mental health" and/or "Yes, physical health" should be automatically directed to a WWA resource page.
The link is: www.BushCenter.org/wwa

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