

Exploring Veterans' Perspectives of their VA Health Data

Report

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Veterans Experience Office | The Lab at OPM
August 2019



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Partners

The VA National Center for Ethics in Health Care

The National Center for Ethics in Health Care serves as VA's authoritative resource for addressing the complex ethical issues that arise in patient care, health care management, and research. They provide information, education, and consultation and oversee nationwide programs and quality improvement projects to help health care practitioners and administrators to understand and apply health care ethics standards.



Veterans Experience Office

As the VA's customer experience organization within the agency, the Veterans Experience Office works across VA administrations, programs and partners to help amplify the perspective of Veterans, their families and caregivers to help improve the customer experience.

The Lab at OPM

The Lab at the US Office of Personnel Management (The Lab at OPM) is a practice that fosters innovation through human-centered design. They teach and propagate human-centered design across the Federal government and help deliver innovative solutions and to address complex public and cross-sector challenges.



Acknowledgments

We are grateful to the Veterans who were interviewed as part of this work. We are also thankful to the following VEO, VA and DoD staff who supported and helped shaped this project: Taray Adkins, Denise Kitts, Helga Rippen, MaryBeth Foglia, Ken Berkowitz, Virginia Ashby Sharpe, Laura Damschroder, and Tanner Caverly.

Executive Summary

Introduction

The Veterans Experience Office and the Lab at OPM is pleased to present this report to the VA National Center for Ethics in Health Care. In April, 2019, the VA National Center for Ethics in Health Care drafted a Pledge for Access to and Use of Veterans' Health Data an ethical framework composed of nine principles (Data Pledge Principles).¹ The intended audience for the pledge was VA employees, with the intention that pledge was drafted for emThe primary focus of this effort was to enlist a human-centered design approach to gain Veteran perspectives about the use and sharing of their health information. Knowing that there are robust efforts, policies and practices across VA that address and inform policies around Veteran health information, this project sought to build on these important frameworks and help uncover opportunities where the individual experiences and perspectives of Veterans might help improve how the pledge might be framed. By speaking directly with Veterans, we gained additional perspectives and considerations that may help inform a Veteran-centric view of how to communicate this pledge to Veterans, their trusted networks and VA itself.

What We Did

Our primary objective was to learn from Veterans and better understand what they expect from VA with respect to the use and sharing of their health data. A small team of designers and strategists from the Lab worked in concert with VA stakeholders from the Veterans Experience Office and the VA National Center for Ethics in Healthcare. A draft pledge meant to be signed by VA employees for access to and use of Veteran Health Data drafted by the VA National Center for Ethics in Healthcare was adapted for use with Veterans. We worked with an abridged set of principles to gain insights and opinions.

What We Found

Through one-on-one conversations, the project team identified key patterns and preferences in how Veterans organized and comprehended summarized versions of the nine principles described in the draft pledge.

What We Propose

Our work with Veterans suggest that at a minimum a reprioritization of the principles and a possible consolidation of overlapping themes should be considered. Additionally, if there are expectations that these principles will be shared with Veterans and employees, creating messaging that accommodates different audiences may be recommended.

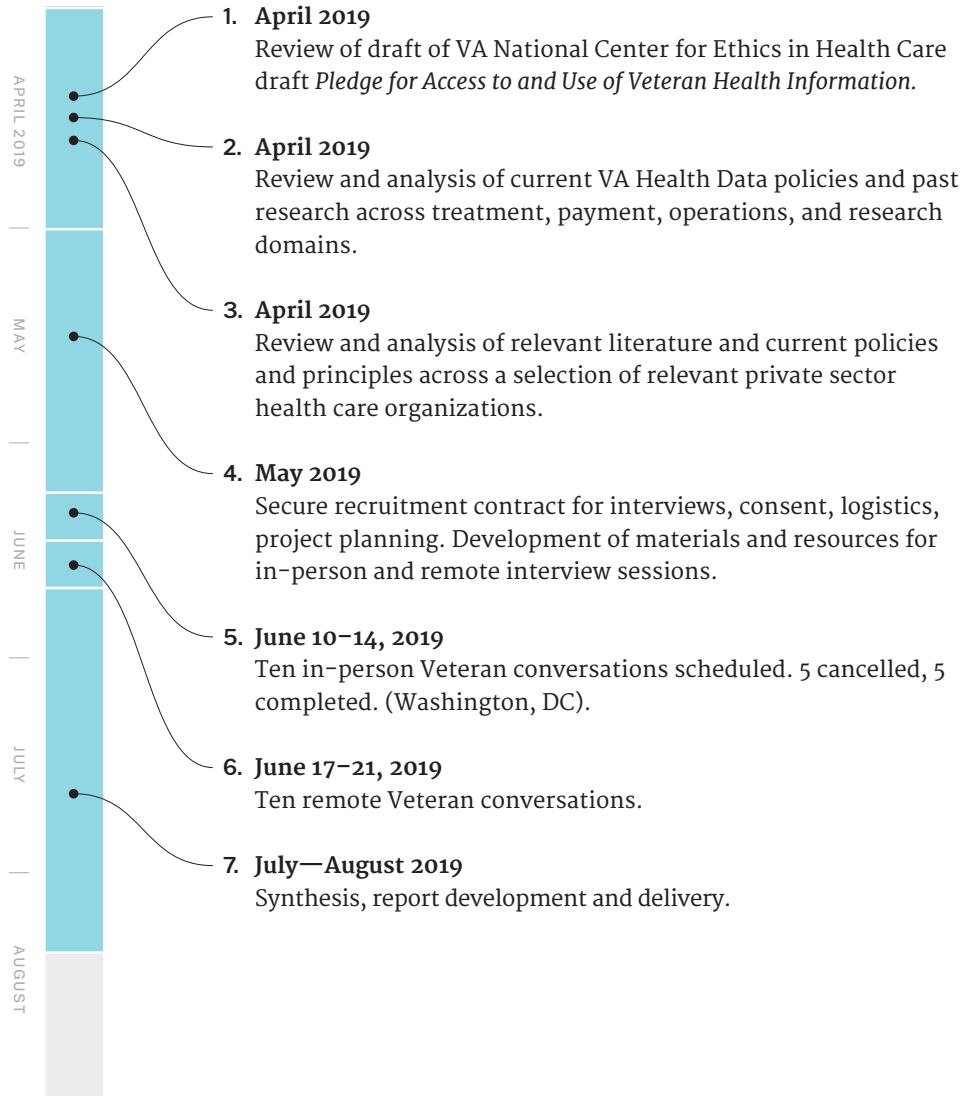
1. See [Appendix 1.0, Pledge for Access to and Use of Veterans' Health Data](#).

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1. What We Did

Project Timeline



1. What We Did

Interviews

Five in-person interviews and 10 virtual conferences were conducted with a diverse set of Veterans. All Veterans were enrolled in VHA health care and all interviewees had experience using MyHealthVet, VA's online patient portal. Participants for in-person and remote interviews were recruited by Perigean Technologies, a VA contractor, and were each compensated \$50 for their time.

In-person interviews were conducted in a conference room at the West End Public Library in Washington, DC. Two team members were present for the in-person interviews. Each interview lasted for about an hour. Veterans were interviewed individually as a facilitator would lead the interviewee through an introduction to the project, and then an exercise leading participants through a review and prioritization of a presentation of the health data principles presented in randomized order. We asked participants to re-order the principles in order of importance to them. Based on the Veteran's personal experience, we also asked if the principles were adequate and if they were missing any additional content or themes. We also asked participants to provide any additional thoughts or changes to the principles. Remote interviews conducted the following week were similar in format. We used a Zoom web conference and walked participants through prioritization of the randomized principles using a tool used for online card sorts called Optimal Workshop.²

We spoke to 15 Veterans³

AGE



INTERVIEW TYPE



GENDER



SERVED IN...



2. Optimal Workshop Online Card Sort URL can be accessed here: <https://adhoc.optimalworkshop.com/optimalsort/health-data>

3. Additional demographics and details on participants can be found in the [Appendix](#).

1. What We Did

Adapted Principles Used in Interviews

Because we were interviewing Veterans, we adapted the existing principles to better accommodate our audience and the open-ended approach to our interviews. We changed the point of view in the original draft principles to reflect a first person perspective and shortened each draft principle to help prompt our participants to more fully share their own impressions. The below tables illustrates the original draft principle and the adapted versions we used during research interviews.

Health data pledge draft principle	Adapted prompt
<p>1. For the good of Veterans Veteran health data is personal and sensitive; access and use should support and improve the delivery of Veteran health and wellness.</p>	<p>My data should be used for the good of Veterans.</p>
<p>2. Equity Use of Veteran health data should help to promote equity so that no Veteran population is excluded from the benefits of data use because race, color, religion, national origin, Limited English Proficiency (LEP), age, sex (includes gender identity and transgender status), sexual orientation, pregnancy, marital and parental status, political affiliation, disability, or genetic information.</p>	<p>My data should be used to promote equity across all Veteran populations.</p>
<p>3. Meaningful choice Sharing of Veterans’ health data – by VA or non-VA parties accessing VA health data – for purposes other than treatment, payment, health care operations, or meeting legal requirements, should be based on the Veteran’s meaningful choice to permit sharing their information for that purpose. Timely, clear, relevant, concise, complete, and comprehensible information must be provided to the Veteran to serve as a basis for their free and informed choice.</p>	<p>I should be able to decide if my data is used for research or commercial reasons.</p>

Table continues on following page →

1. What We Did

▶ ADAPTED PRINCIPLES USED IN INTERVIEWS

Health data pledge draft principle	Adapted prompt
<p>4. Transparency Access to and exchange of VA patient data should be transparent and consistent, and in accord with practices described in VA’s Notice of Privacy Practices. Data should only be accessed by VA or other parties for approved, and/or specified purposes; there should be no un-specified use, or re-use of Veterans’ data. Re-release of Veteran data for purposes other than treatment, payment, health care operations, or to meet legal requirements should require a commitment of the new party/entity to follow this pledge. Failure to assure such protections is a breach of Veteran trust and confidentiality.</p>	<p>When my data is used, the purpose must be specified and I should be notified.</p>
<p>5. Principled de-identification Parties who receive Veterans’ de-identified data should not attempt to reidentify the data in any manner without prior authorization; unauthorized re-identification is a breach of Veteran trust and confidentiality.</p>	<p>If my de-identified data is re-identified, I would need to authorize it.</p>
<p>6. Reciprocal obligation for Veteran data use Financial gain or health innovation resulting from use of Veterans’ data creates an obligation of reciprocity to share this gain with Veterans, or Veterans organizations and causes. At a minimum, any secondary benefits to users of VA data, as well as resulting contributions to Veterans and/or VA, should be publicly disclosed.</p>	<p>If use of my data has resulted in an innovation, benefit, or financial gain this should be shared with Veterans, Veteran causes or publicly disclosed at a minimum.</p>
<p>7. Obligation to ensure data security, quality, integrity Parties who send, receive, or use Veterans’ data must assure data security, quality, and integrity; that is, that the data remains secure, accurate, complete, and representative of the data quality and integrity accessed from VA.</p>	<p>My data should be secure, protected, accurate, and complete.</p>

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1. What We Did

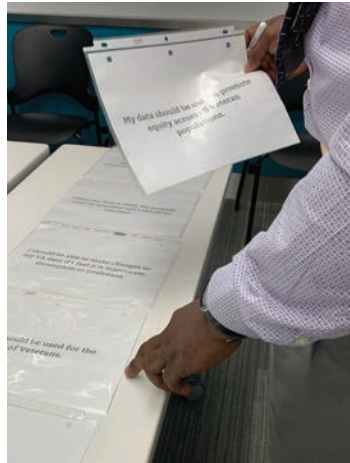
▶ ADAPTED PRINCIPLES USED IN INTERVIEWS

Health data pledge draft principle	Adapted prompt
8. Veteran access to their own information Veterans should have user-friendly access to their own electronic health information.	I should be able to easily access my own health data.
9. Veteran right to request amendment to their own information Veterans should be able to exercise their right to request amendments to their information if they feel it is inaccurate, incomplete, or not relevant to their health or wellness.	I should be able to make changes to my VA data if I feel it is inaccurate, incomplete or irrelevant.

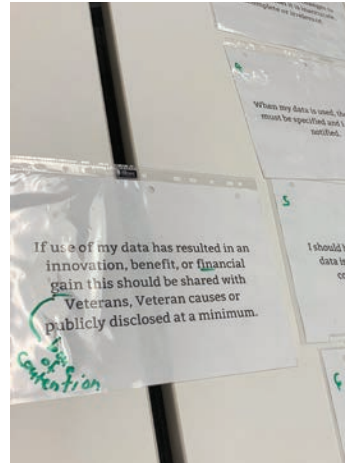
1. What We Did

Approach: in-person interviews

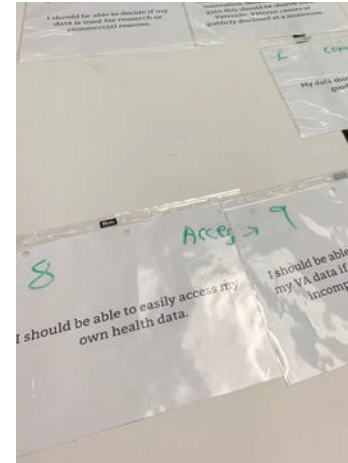
After introducing ourselves and the project, we presented the adapted principles in randomized order and first asked our participants to rank the principles in order of importance to them (See photo 1). After participants completed the ranking exercise, they talked through their rationale and sometimes provided us with additional comments and considerations (photo 2). Participants would also group principles together if their importance was similar or when some principles seemed duplicative. Additionally, if participants felt a theme was missing from the prompts, they added additional input on an index card (photo 4).



1. Ranking exercise



2. Additional probes asked participants the reasons for their rankings. e.g., "Why did you rank your #1 most important or your #9 least important?"



3. After ranking, some participants annotated relevant prompts with their interpretations and thoughts. We recorded when rankings were similar and if participants grouped the principles into themes.

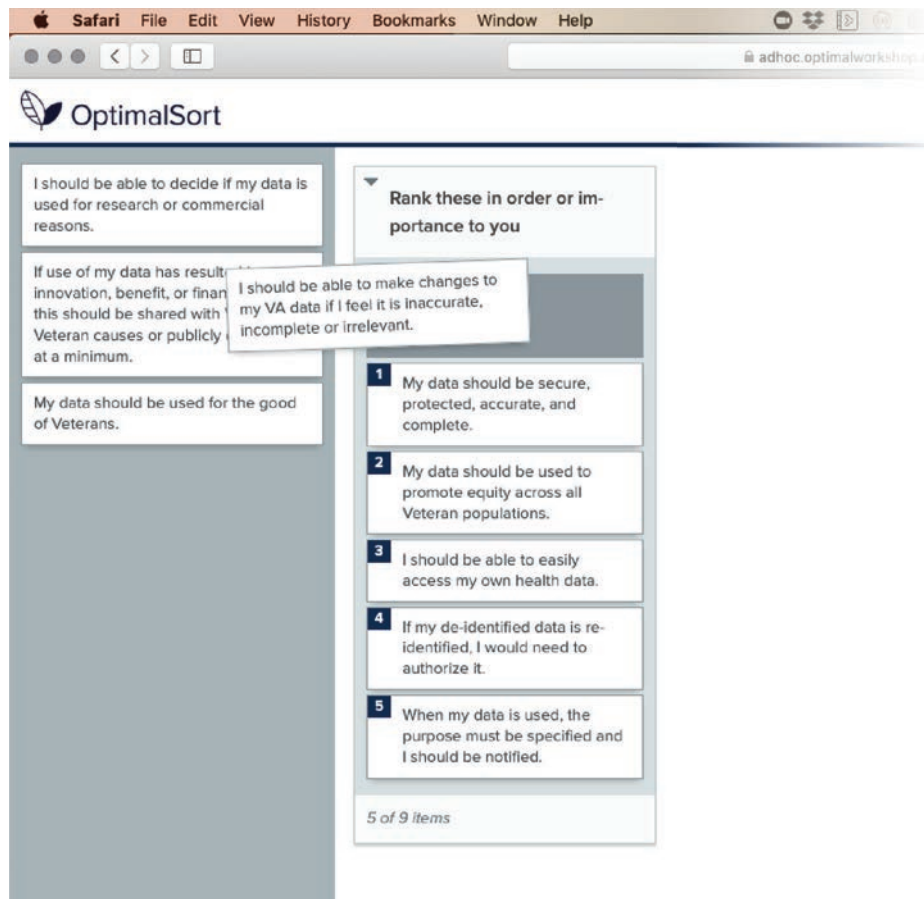


4. We also asked participants if they felt any important principles or considerations were missing and asked for them to add their own.

1. What We Did

Approach: remote interviews

Remote interviews were generally shorter in length and were usually conducted one-on-one with a single facilitator through a Zoom web conference. We used an online tool called Optimal Workshop (Optimal Sort) to facilitate the ranking exercise online. The facilitator led the interviewee through the ranking exercise and took notes during the interviews.



Screen capture of an online ranking exercise

What We Found

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2. What We Found

Interview results

After reviewing cumulative results from the ranking exercise, Veterans generally prioritized the principles in reverse of the order in the drafted document—possibly reflecting an individuals’ perspective rather than an organizational one.

Additionally, participants helped to further clarify and group some of the principles into their own assigned categories or themes. The themes created were:

Access

Community Sharing

Consent of Use

How Data is Used

Security & Privacy

Veterans Experience

What Data is Used For

Prioritization of principles, average order of importance position (1-9), applicable Veteran comments or quotes in response to a specific principle, recommendations based on evidence from that principle, and suggested groupings for the principles are reflected in the graphic (table) below. In addition to recommendations cited below, a few of our participants additionally considered the legacy of their health data and mentioned that the principles failed to address policies around Veteran health data posthumously.

2. What We Found



▶ INTERVIEW RESULTS

Veteran-facing abridged Principle	Average ranking	Existing order	Selected Veteran Comment	Summary / recommendation	Suggested themes
A) My data should be secure, protected, accurate, and complete.	2.1	7	“Sometimes I have concerns about the quality of my data. Doctors can be inconsistent when it comes to note taking.” —Army Veteran, M	Participants expressed significant concerns around security, quality, and accuracy of their health information.	<ul style="list-style-type: none"> Security & Privacy Veterans Experience
B) I should be able to easily access my own health data.	2.8	8	“Active duty records don’t transfer to VA, you have to tell your story over and over again.” —Army Veteran, M	Participants with a history on active duty expressed frustration with VA not having access to DoD and private sector/Tricare records.	<ul style="list-style-type: none"> Access Veterans Experience
C) When my data is used, the purpose must be specified and I should be notified.	4.6	4	“Veteran data should be accessed by only designated or assigned VA personnel.” —Army Veteran, M	Multiple participants addressed the issue of access and permissions.	<ul style="list-style-type: none"> Security & Privacy How Data is Used What Data is Used For
D) If my de-identified data is re-identified, I would need to authorize it.	4.6	5	“A lot of sensitive information (like mental health notes I wouldn’t want others to see.” —Air Force Veteran, F	Veterans expressed concern about this principle but wanted examples of when this circumstance would arise.	<ul style="list-style-type: none"> Security & Privacy How Data is Used
E) I should be able to make changes to my VA data if I feel it is inaccurate, incomplete or irrelevant.	4.9	9	“Having the Veteran vet that data is a good thing and can lead to the accuracy of that information.” —Air Force Veteran, M	Veterans expressed concerns around the challenges of correcting inaccurate information or supplementing incomplete information.	<ul style="list-style-type: none"> Access Veterans Experience

Table continues on following page →

2. What We Found

▶ INTERVIEW RESULTS

Veteran-facing abridged Principle	Average ranking	Existing order	Selected Veteran Comment	Summary / recommendation	Suggested themes
F) My data should be used for the good of Veterans.	6.1	1	<p>“[VA] should be able to get something from us...there’s a good opportunity for medical research and the greater good.”</p> <p>—Air Force Veteran, F</p>		<p>Community Sharing</p> <p>What Data is Used For</p>
G) I should be able to decide if my data is used for research or commercial reasons.	6.1	3	<p>“I think that both purposes are valid, however, I also surmise that the veteran population will want to know that the distinction exists and in what ways it benefits the public.”</p> <p>—Army Veteran, M</p>		<p>Consent of Use</p> <p>How Data is Used</p>
H) If use of my data has resulted in an innovation, benefit, or financial gain this should be shared with Veterans, Veteran causes or publicly disclosed at a minimum.	6.4	6	<p>“I should have a choice if my data is used. I would expect them to contact me and give me the options.”</p> <p>—Marine Veteran, M</p>	<p> Consider merging with row (G).</p>	<p>Consent of Use</p> <p>What Data is Used For</p>
I) My data should be used to promote equity across all Veteran populations.	7.3	2	<p>“I don’t like the principle of somebody poops, everybody wears a diaper...things should be tailored to individual needs.”</p> <p>—Army Veteran, M</p>	<p> Consider merging with row (F).</p>	<p>Community Sharing</p> <p>What Data is Used For</p>

What We Propose

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3. What We Propose

Principles: Order



We propose that the health data principles be reordered to reflect the cumulative order of importance of the principles that we determined in our research displayed below.

Ranking, in order of importance	Draft principle heading	Veteran-facing abridged principle
1	Obligation to ensure data security, quality, integrity	My data should be secure, protected, accurate, and complete.
2	Veteran access to their own information	I should be able to easily access my own health data.
3 (tie)	Transparency	When my data is used, the purpose must be specified and I should be notified.
	Principled de-identification	If my de-identified data is re-identified, I would need to authorize it.
5	Veteran right to request amendment to their own information	I should be able to make changes to my VA data if I feel it is inaccurate, incomplete or irrelevant.
6 (tie)	For the good of Veterans	My data should be used for the good of Veterans.
	Meaningful choice	I should be able to decide if my data is used for research or commercial reasons.
8	Reciprocal obligation for Veteran data use	If use of my data has resulted in an innovation, benefit, or financial gain this should be shared with Veterans, Veteran causes or publicly disclosed at a minimum.
9	Equity	My data should be used to promote equity across all Veteran populations.

3. What We Propose

Principles: Consolidation

Some participants felt that the **Equity** and **For the Good of Veterans** (ranked 5 & 7 above) principles were redundant and could be consolidated into a single principle. Additionally we heard the same feedback for **Reciprocal Obligation for Veteran Data Use** and **Meaningful Choice** (ranked 5.1 & 6 above).

	Draft principle heading	Veteran-facing abridged principle
 Suggested Merge	Equity	My data should be used to promote equity across all Veteran populations.
	For the good of Veterans	My data should be used for the good of Veterans.
 Suggested Merge	Reciprocal obligation for Veteran data use	If use of my data has resulted in an innovation, benefit, or financial gain this should be shared with Veterans, Veteran causes or publicly disclosed at a minimum.
	Meaningful choice	I should be able to decide if my data is used for research or commercial reasons.

3. What We Propose

Principles: Themes

Veterans also grouped these principles into themes which they generated during our discussions and are displayed in Table/Illustration on [page 15](#).

Participants grouped principles into a number of themes including:

Access

Community Sharing

Consent of Use

How Data is Used

Security & Privacy

Veterans Experience

What Data is Used For

3. What We Propose

Recommendations

Incorporating the Veteran's Voice: Timing is Everything

By interviewing Veterans about their opinions of the Data Pledge Principles, we added their voices to the conversation about VA health data and why these principles are important to uphold. The structured interviews allowed us to uncover opportunities for shaping attitudes and leveraging intrinsic motivations of Veterans in shaping relationships to health data, to the VHA, and to health care more broadly. This conversation becomes tangibly more dynamic, relevant and meaningful when we include the voices of those we are trying to serve.

While the conversation around these principles was made richer by bringing Veterans to the table, there was a missed opportunity to do even more to incorporate their insights, leverage their perspectives and address their unmet needs. By bringing Veterans to the table as initiatives such as these are being formed—rather than at the point of implementation—the outcomes become more relevant and meaningful to all involved. The difference between a rich and validating conversation that provides valuable feedback on an existing artifact or service and an engagement that shapes an outcome with resonance across the board is simply a matter of when the conversation happens.



“When Veterans don’t see themselves represented, they won’t trust VA.”

—Army Veteran

3. What We Propose

Recommendations

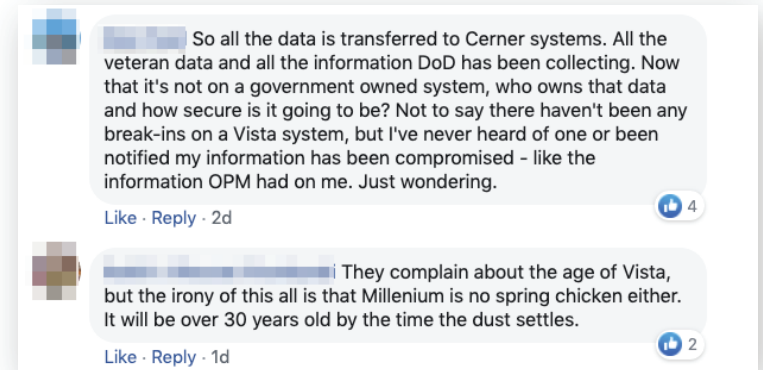
Based on our conversations with Veterans, we recommend that the Draft Health Data Principles be adapted for a Veteran audience – reflecting the priority of importance of the principles across Veterans populations. We additionally ask that the authors of the document consider how to present these principles in ways that could better educate Veterans and Staff about VA health data.

Security, access and control of an individual’s health data were identified most prominently as the most important themes across the principles for participants.

Below, the EHRM story and Facebook comments posted in response on July 29, 2019.

Find opportunities to educate when VA health data is in the news

Given the recent news release⁴ from the VA Electronic Health Record Modernization (EHRM) team declaring that the records of 23.5M Veterans had recently been transferred to Cerner data centers, milestones like this present important opportunities to create additional campaigns to create an ongoing dialogue as health data becomes more fluid across government and private sector systems. After the EHRM team announced the Cerner Veteran data migration, a comment cropped up on the VistA Group on Facebook expressing concern about Cerner’s data ownership and security. These events create critical opportunities for outreach and education for VA, and upholding the principles they are trying to steward.



4. The story can be accessed here: <https://federalnewsnetwork.com/veterans-affairs/2019/07/vas-plans-for-maintaining-vista-spark-cost-concerns-for-new-electronic-health-record/>

Appendix

<i>Draft Pledge for Access to and Use of Veterans' Health Data</i>	23
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1.0 Draft Pledge for Access to and Use of Veterans' Health Data

Page 1

PREDECISIONAL DRAFT VERSION 5 FOR INTEROPERABILITY WORKGROUP COMMENT
4/04/19 - DO NOT CIRCULATE OR DISSEMINATE WITHOUT PERMISSION

Department of Veterans Affairs Pledge for Access to and Use of Veterans' Health Data

Veterans trust VA to promote and respect their privacy, confidentiality, and autonomy in the services we provide and enable. VA embodies this trust when we adhere to VA's **I CARE** core values of Integrity, Commitment, Advocacy, Respect, and Excellence. As a learning organization, VA advances Veteran health and wellness by promoting responsible use of Veterans' data; that is, continuously assuring strong data stewardship practices while using Veterans' data to advance both Veteran and Public Health. The following principles establish an ethical framework for individuals, groups, or entities inside and outside VA who access and/or use Veterans' data. Specific clinical, technical, fiscal, regulatory, and industry standards should operate within this ethical framework to ensure the integrity and trustworthiness that Veterans and other stakeholders expect and deserve.

Principle 1: For the good of Veterans

Veteran health data is personal and sensitive; access and use should support and improve the delivery of Veteran health and wellness.

Principle 2: Equity

Use of Veteran health data should help to promote equity so that no Veteran population is excluded from the benefits of data use because race, color, religion, national origin, Limited English Proficiency (LEP), age, sex (includes gender identity and transgender status), sexual orientation, pregnancy, marital and parental status, political affiliation, disability, or genetic information.

Principle 3: Meaningful choice

Sharing of Veterans' health data – by VA or non-VA parties accessing VA health data – for purposes other than treatment, payment, health care operations, or meeting legal requirements, should be based on the Veteran's meaningful choice to permit sharing their information for that purpose. Timely, clear, relevant, concise, complete, and comprehensible information must be provided to the Veteran to serve as a basis for their free and informed choice.

Principle 4: Transparency

Access to and exchange of VA patient data should be transparent and consistent, and in accord with practices described in VA's Notice of Privacy Practices. Data should only be accessed by VA or other parties for approved, and/or specified purposes; there should be no un-specified use, or re-use of Veterans' data. Re-release of Veteran data for purposes other than treatment, payment, health care operations, or to meet legal requirements should require a commitment of the new party/entity to follow this pledge. Failure to assure such protections is a breach of Veteran trust and confidentiality.

Principle 5: Principled de-identification

Parties who receive Veterans' de-identified data should not attempt to reidentify the data in any manner without prior authorization; unauthorized reidentification is a breach of Veteran trust and confidentiality.

1.0 Draft Pledge for Access to and Use of Veterans' Health Data

Page 2

PREDECISIONAL DRAFT VERSION 5 FOR INTEROPERABILITY WORKGROUP COMMENT
4/04/19 – DO NOT CIRCULATE OR DISSEMINATE WITHOUT PERMISSION

Principle 6: Reciprocal obligation for Veteran data use

Financial gain or health innovation resulting from use of Veterans' data creates an obligation of reciprocity to share this gain with Veterans, or Veterans organizations and causes. At a minimum, any secondary benefits to users of VA data, as well as resulting contributions to Veterans and/or VA, should be publicly disclosed.

Principle 7: Obligation to ensure data security, quality, integrity

Parties who send, receive, or use Veterans' data must assure data security, quality, and integrity; that is, that the data remains secure, accurate, complete, and representative of the data quality and integrity accessed from VA.

Principle 8: Veteran access to their own information

Veterans should have user-friendly access to their own electronic health information.

Principle 9: Veteran right to request amendment to their own information

Veterans should be able to exercise their right to request amendments to their information if they feel it is inaccurate, incomplete, or not relevant to their health or wellness.

I/WE PLEDGE TO ACT WITH INTEGRITY IN ACCORDANCE WITH THE ETHICAL PRINCIPLES SET FORTH HEREIN.

SIGNED: _____ DATED: _____

CONCERNING THE FOLLOWING DATA ACCESS AND USE: _____

4. Appendix

2.0 Detailed Interviewee Demographics

	Interview Type	Gender	Race/ Ethnicity	Age Range	Branch	State of Residence	Education
1	Remote	M	White	35-44	Army	DC	Master's degree
2	In-Person	F	White	35-44	Army	MD	Some college (no degree)
3	In-Person	M	Black or African	35 -44	Army	MD	Master's degree
4	In-Person	M	White	25-34	Army	VA	Master's degree
5	In-Person	M	White	25-34	Air Force	DC	Bachelor's degree
6	In-Person	F	White	45-54	Air Force	VA	Bachelor's degree
7	Remote	F	White	35-44	Army	AL	NA
8	Remote	F	Hispanic/Latino	25-34	Air Force	CA	Doctorate
9	Remote	M	White	55-64	Marines	CA	Some college (no degree)
10	Remote	M	White	65-74	Marines	CA	Some college (no degree)
11	Remote	M	White	35-44	Air Force	DE	Master's degree
12	Remote	F	Hispanic/Latino	25-34	Air Force	CA	Some college (no degree)
13	Remote	M	White	65-74	Army	MN	Master's degree
14	Remote	F	White	55-64	Air Force	TN	Bachelor's degree
15	Remote	M	Asian	25-34	Army	CA	Master's Degree

3.0 Further Reading

1. Parasidis, E., Pike, E., & McGraw, D. (2019). A Belmont Report for Health Data. *New England Journal of Medicine*, 380(16), 1493–1495. doi: 10.1056/nejmp1816373
2. Perakslis, E., & Coravos, A. (2019). Is health-care data the new blood? *The Lancet Digital Health*, 1(1). doi: 10.1016/s2589-7500(19)30001-9
3. Stanford Libraries. (2019) Statement of Guiding Principles for Ethics in Digital Health. A set of 10 Guiding Principles resulting from two seminars comprised of cross-sector representatives. Retrieved from: <https://library.stanford.edu/digitalhealthethics/guiding-principles>
4. U.S. Department of Veterans Affairs Electronic Health Record (VA EHR) Modernization Website. Retrieved from: <https://www.ehrm.va.gov/>