



The Lab at OPM

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Exploration of Veterans Perspectives of their VA Health

Data

Veteran Recruitment Request

Jane Newman

Veterans Experience Office/Lab at OPM

5/21/19

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Background

The Veterans Experience Office, the VA National Center for Ethics in Healthcare, and the VA DOD Interagency Program Office are embarking on an effort to develop a clearer understanding of Veteran perspectives about the use and sharing of their health information. The VA National Center for Ethics in Health Care has developed a draft pledge *Pledge for Access to and Use of Veterans' Health Data* which describes nine principles for VA stewardship of Veteran health data (attached).

Goals

While we are planning on working with these draft principles as part of the exploration, we hope to get additional insight directly from Veterans so that we can develop a framework that reflects the wants and needs of Veterans with respect to their health data.

Research Questions & Methods

A research plan is attached. We are planning a mixed method approach that includes a combination of a directed interviews combined with a short card sort (for the principles).

Participants & Recruitment

We are looking to identify approximately 20 Veterans for interviews. This includes:

- 10 Veterans in person in New York NY, Washington DC, and Boston MA
- 10 remaining interviews with Veterans from across the country who would be able to participate in an interview using a Zoom web conference call.
- Interviewees should come from a cross-section of ages, genders, service eras, and socioeconomic backgrounds.
- Of the participants, at least 16/20 should have a My HealtheVet Account that they use actively. If there is a circumstance where a Veteran has a proxy or relative that manages their information online, we would like to be able to have that person join us in an interview.

Timeline

Estimated Recruitment Date Range	5/27/2019	6/7/2019
DC Interviews	6/10/2019	6/14/2019
Boston Interviews	6/17/2019	6/19/2019
New York City Interviews	6/20/2019	6/21/2019
Remote Interviews	6/10/2019	6/28/2019

Team Roles

Name (Based in)	email	Role	Location
Jane Newman	jane.newman3@va.gov	moderator, research guide writing, project POC	Boston, New York, DC
Patty Beirne (Lab)	patty.beirne@opm.gov	moderator, notetaker	New York, DC
Erin Siminerio (DC)	erin.siminerio@va.gov	notetaker	remote
Taray Adkins	taray.adkins@va.gov	observer, recruiting	remote
Eulani Labay	eulani.labay@opm.gov	moderator, notetaker	New York

Sessions

Each session will last for a maximum of one hour. All team members are located in the Eastern time zone and can accommodate hours outside 9-5 if needed.

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.

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: _____



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Project Plan

DRAFT

Jane Newman, Patty Beirne

Veterans Experience Office/Lab at OPM

4/23/19

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Introduction

The Veterans Experience Office and the Lab at OPM is pleased to present this Project Plan to the VA National Center for Ethics in Health Care. The primary focus of this effort is to develop a clearer understanding of Veteran perspectives about the use and sharing of their health information and how Veterans and their trusted support networks expect it should be handled across the complex information ecosystem of VA and beyond.

Today, there is a crisis of confidence in how many digital media platforms handle user privacy. With an increasingly seamless capability to share health data through APIs, now is an opportune time to delve into the issues to gain insights into what Veterans expect from VA regarding their health information.

Objectives

Our primary objective is to learn from Veterans and better understand what they expect from VA with respect to the use and sharing of their health data.

Scope

A small team of designers and strategists from the Veterans Experience Office and the Lab at OPM will work in concert with VA stakeholders from the VA National Center for Ethics in Healthcare to bring the project to completion.

Stakeholders/SMEs

Name (Based in)	Organization	Team
Jane Newman (Boston) (Lab) Patty Beirne (Lab) Denise Kitts (DC) Erin Siminerio (DC) Dave Leonard (Detroit) Taray Adkins (Chesapeake, VA)	Lab at OPM, Veterans Experience Office	Project Team

Helga Rippen (DC)	VA DOD Interagency Program Office	SME
Ken Berkowitz (NYC) Virginia Sharpe (DC) Mary Beth Foglia (Seattle)	VA National Center for Ethics in Healthcare	SME
Laura Damschroder (Ann Arbor) Tanner Caverly (Ann Arbor) Michelle Gornick (Ann Arbor)	Ann Arbor VA Center for Clinical Management Research/COIN	Ad hoc SMEs (Have done similar work on the topic in the past)
Theresa Hancock	MyHealtheVet (MHV)	Possible assistance with recruitment through MHV Coordinators and Users

Approach

Discovery

Currently in progress, the discovery phase involves literature reviews, research, planning, and analysis before embarking on field interviews. Most resources circulated by the team via email can be accessed through VA Pulse in this account:

<https://www.vapulse.net/groups/exploring-veteran-perspectives-on-health-data>

The following is underway:

- ✓ Review and analysis of current VA Health Data policies and past research across treatment, payment, operations, and research domains.
- ✓ Review and analysis of relevant literature and current policies and principles across a selection of relevant private sector health care organizations.
- ✓ Recruitment strategy for interviews through MyHealtheVet and possibly other channels
- ✓ If possible, a card sort exercise with MHV users (sent through email list) to get an idea of preferences for current principles.
 - <https://adhoc.optimalworkshop.com/optimalsort/health-data>

Fieldwork

Fieldwork primarily involves either in-person interviews or conference calls with Veterans. To eliminate the costs related to travel, we will focus on sites where local team members live and virtual interviews.

We estimate that we will need 60-minutes of uninterrupted time with 10-20 Veterans to gather meaningful insights about the topics. VEO and program contacts will help with arranging interviews, meeting space, conference calls and logistics. If there are opportunities to work with staff from the National Center for Ethics in Health Care either virtually or on-site, we would be happy to include staff in interview activities if time and schedules permit.

Estimated Schedule

	Start Date	End Date
Discovery & Surveys	5/1/2019	6/14/2019
Recruitment	5/27/2019	6/7/2019
DC	6/10/2019	6/14/2019
Boston	6/17/2019	6/19/2019
New York City	6/20/2019	6/21/2019
Remote Interviews	6/10/2019	6/28/2019
Synthesis	7/1/19	7/12/2019
Final Deliverable	7/15/2019	7/31/2019

Methodology

1:1 Contextual Inquiry

60-minute 1:1 moderated live (or phone) interviews with Veterans.

- **Recruiting/Screening:** 10-20 Veterans recruited from MHV (those with Blue Button downloads, MHV Coordinators, and others TBD).
- **Debriefing:** The project team will debrief for 60 minutes at the conclusion of the day
- **Research Artifacts:** Verbatim notes, debrief notes, consent forms will be organized and stored on VA Pulse.
- **Analysis:** Key findings will be presented informally. The research will feed directly into the Principles document and any related artifacts.

Greeting

Hello, thank you for joining us today!

Do you have about 60 minutes to spend with us today?

Informed consent (~2m)

[VA Veteran Health Data Perspectives Project Consent Form](#)

About the conversation (~3m)

Thank you for making the time to meet with us today. My name is _____, and this is _____.

We are working on a project to understand your experiences with VA healthcare, and your thoughts about your how your health information is used. In the past, the VA hasn't done a great job listening to Veterans' needs, so we're trying to change that.

My colleague _____ will be listening carefully to you and taking notes while you and I talk. I am going to ask you general questions about your experience with the military, then more specific questions about how you manage your health information and what your expectations are around it. We are interested in hearing your thoughts and opinions. You are an expert in your own experience and we are here to learn from you. Your voice is important because it helps us understand how we can improve. There are no wrong and right answers to these questions. We are just interested in your ideas.

- As I speak to you today, I may sound like I'm asking "why" a lot. That's because I want to make sure I capture your details correctly.
- Before I ask you a few background questions, I want to remind you that your job is really easy, you just have to be yourself and act as you naturally would.
- As we talk today, please be honest with your positive and negative thoughts.
- Nothing you say will hurt my feelings.
- I will now begin recording the session (make sure to tap record!)

First would you tell me a little bit about yourself. When did you Serve in the military and where? What was that like for you?

- What military branch were you in?
- Did you deploy overseas? Were you ever involved in combat?
- Is there anything else we should know about you?
- How long have you been using VA Health Care?
- Do you use MyHealtheVet?

Thinking about the times when VA has handled your health information are there any situations that stand out in any way, positive or negative?

- What was that like for you?

- How did this make you feel? How would you like to feel?
- How were you able to get what you needed?
- Would you have liked anything to be different?

Thinking about the times when you needed to access your VA health information are there any situations that stand out in any way, positive or negative?

- What was that like for you?
- How did this make you feel? How would you like to feel?
- How were you able to get what you needed?
- Would you have liked anything to be different?

What type of information do you believe VA has about you?

- What do you believe would be appropriate use?
- What do you trust VA to do with your information?

[Open ended conversations meant to elicit meaning feedback and insights from participants]

Rank the following in order of importance to you.

My data should be used for the good of Veterans. (P1)

My data should be used to promote equity across all Veteran populations. (P2)

I should be able to decide if my data is used for research or commercial reasons (P3)

When my data is used, the purpose must be specified and I should be notified. (P4)

If my de-identified data is re-identified, I would need to authorize it. (P5)

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. (P6)

My data should be secure, protected, accurate, and complete. (P7)

I should be able to easily access my own health data. (P8)

I should be able to make changes to my VA data if I feel it is inaccurate, incomplete or irrelevant. (P9)

Exit

- Well, [participant name] that does it for us. Your input is very important to us and I want to thank you.

Debrief

- What did participants do?
- How did participants characterize what they did? Use their words.
- What did you see going on?
- What surprised you?
- What did you learn in that session?