HARVARD UNIVERSITY - APRIL 27, 2018

FAMILY CAREGIVERS

JEANETTE

Mother to Iraq War Veteran

Experienced in daily care of daughter

Looked for help after daughter's injury

In search of "me time"

BRYCE

Husband to Afghanistan War Veteran

New role following her return from tour

Found guides from Veterans Affairs

Seeking tools and community

5.5 million

approximately 5.5m caregivers across the United States care for wounded service members or Veterans

family caregiver

a **family caregiver** is any supporter who plays a role in managing care for a Veteran who requires assistance for **visible or invisible wounds**

How might we…

enable the U.S. Department of Veterans Affairs [VA] and the U.S. Digital Service at the VA [DSVA] to **better support family caregivers** in meeting their complex needs?

MEET TEAM #VA_CAREGIVERS

An integrated team with cross-disciplinary skill sets – design, engineering, product development, research, writing, and policy – established to link Harvard to **family caregiver needs**.
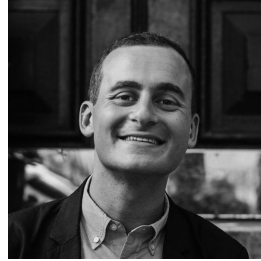
AMELIA SAMPAT

Strategist, Digital Execution

KATHERINE SPIES

Engineer, CTO, Veteran

MATTHEW SPECTOR

Writer, Researcher, Journalist

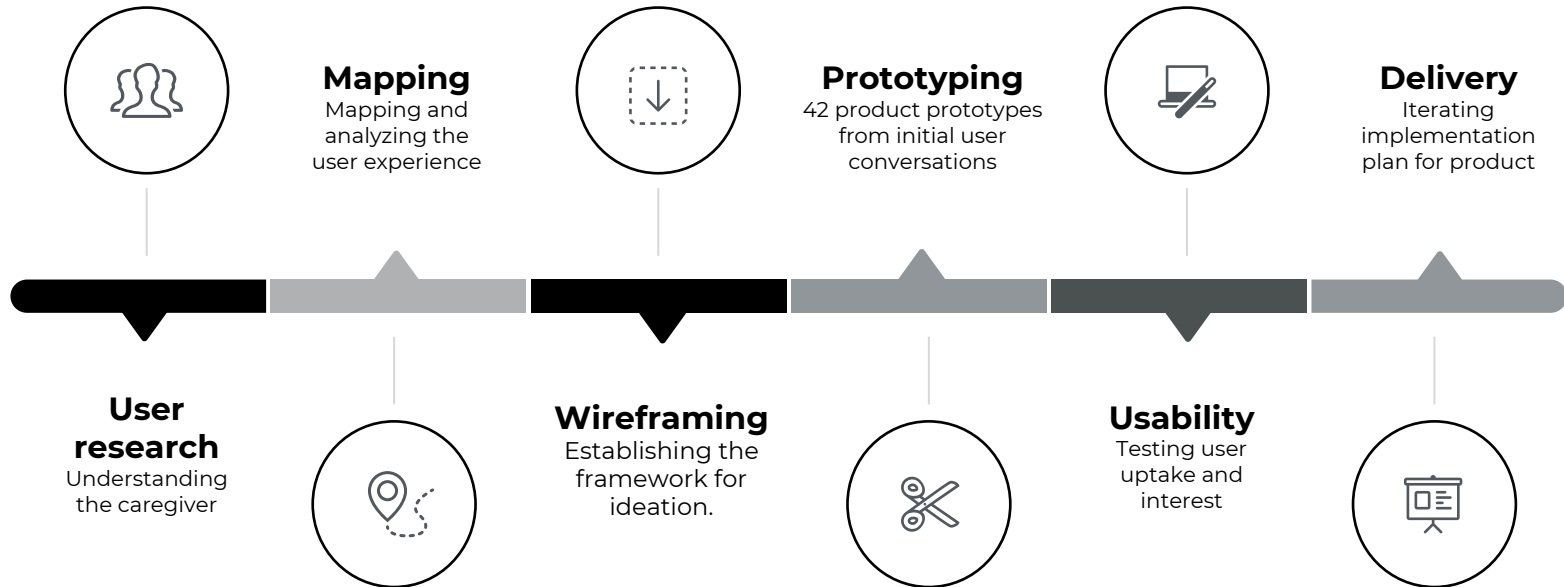## BRANDON LEE

Developer

DANI CINALI

Consultant, User Researcher

40+ INTERVIEWS

More than 40 interviews with experts, caregivers, and coordinators and evolved from research to concept validation through user testing.

Mapping
Mapping and analyzing the user experience

Prototyping
42 product prototypes from initial user conversations

Delivery
Iterating implementation plan for product

User research
Understanding the caregiver

Wireframing
Establishing the framework for ideation.

Usability
Testing user uptake and interest

CAREGIVER INSIGHTS

Key insights into the caregiver – and caregiving – experience.

NO FORMAL ONBOARDING

Caregivers don't always know they are filling the role of a caregiver, but rather are just doing what needs to be done. Acknowledgement of the role often occurs when help is most needed and caregiver must acclimate with little initial support or guidance.

LIMITED SOCIAL SUPPORT

Local and social media caregiver networks not only fill in the gaps around VA guidance and training, but are critical sources of emotional support and friendship.
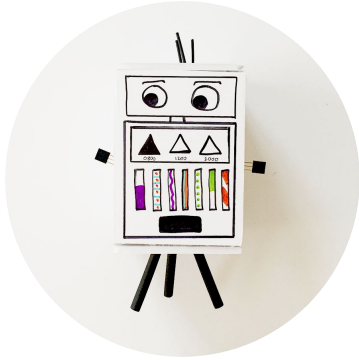
VETERAN-FIRST MINDSET

Caregivers put the Veteran first, absorbing the Veteran's pain while silently struggling and deprioritizing time for themselves.

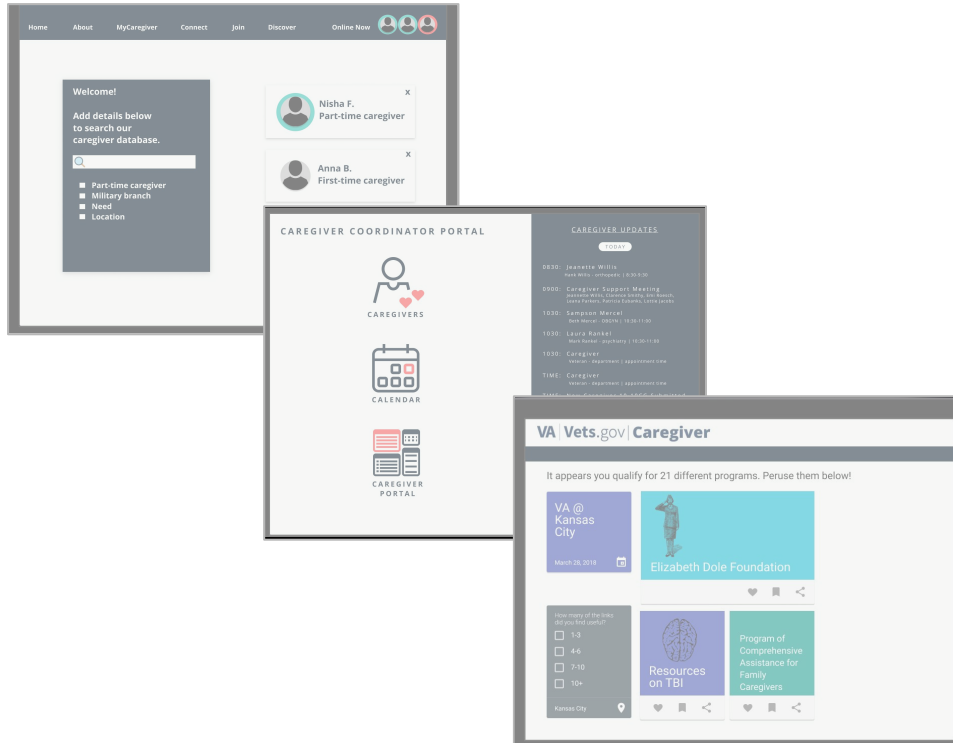## SEEKING "NORMAL"

Caregivers strive for normalcy but grapple with the extent of caregiving demands, the unpredictability of their schedules, and anxiety over leaving the Veteran alone.

42 PROTOTYPES

42 prototypes, 3 advance to the next round of iterations and development.

THREE TEST CONCEPTS, 12+ USER TESTS

Testing three user concepts with experts, caregivers, and coordinators.

PROBLEM

SOLUTION

> **NO FORMAL ONBOARDING**

> **LIMITED SOCIAL SUPPORT**

> **VETERAN-FIRST MINDSET**

> **SEEKING "NORMAL"**

Integrated portal
connecting caregivers
and coordinators

VA CAREGIVER PORTAL

A dedicated portal for caregivers, offering and linking identity.

CAREGIVER ID

Secure caregiver login to ensure compliant ID management.

MESSAGING

Direct, secure messaging with coordinator and, ultimately, providers.

CAREGIVER PROFILE

Dedicated profile allows recognition and personalized service..

RESOURCES

Customized resource library.

VA CAREGIVER PORTAL

FAMILY CAREGIVERS

ABOUT   HOME   RESOURCES   PROFILE

My Updates

+ ELIZABETH DOLE FOUNDATION has added a resource

+ BLUE STAR FAMILIES has added

+ CAREGIVER.ORG has added an

+ NEW upvotes on your resource

+ NEW meetup for Iraq Conflict

Caregiver Updates

+ NEW Caregiver benefit inform

+ UPDATED Health guidance

+ NEW Telehealth training

+ REVISED Respite care updates

+ UPDATED Monthly caregiver news and views

My Messages

Find My Coordinator

Notification   X

Good morning Jeanette!
You are now entering the secure Vets.gov caregiver portal.

NEXT

Wilis, Jeanette   CONNECT WITH VA

FAMILY CAREGIVERS

ABOUT   HOME   RESOURCES   PROFILE

Based on your profile, here are the resources most relevant to you. Click to expand relevant resources, save resources for future use, and x the resources you'd prefer not to see again:

FOR YOU

Elizabeth Dole Foundation
details: caregiver tools, respite, community
click to expand

Psycharmor
details: caregiver tools, respite, community
click to expand

American Red Cross MVCN
details: connection, aid and support
click to expand

SAVED

Elizabeth Dole Foundation
details: caregiver tools, respite, community
click to expand

LOCAL

La Jolla Caregivers
details: local resources, meetups
click to expand

SoCal Community
details: Gulf-era veteran tools, part-time work
click to expand

Morning Fitness San Diego
details: therapy, self-care and fitness
click to expand

La Jolla – Gulf Conflict
details: conversation and tips
click to expand

Click to search for VA-approved resources.

SEARCH

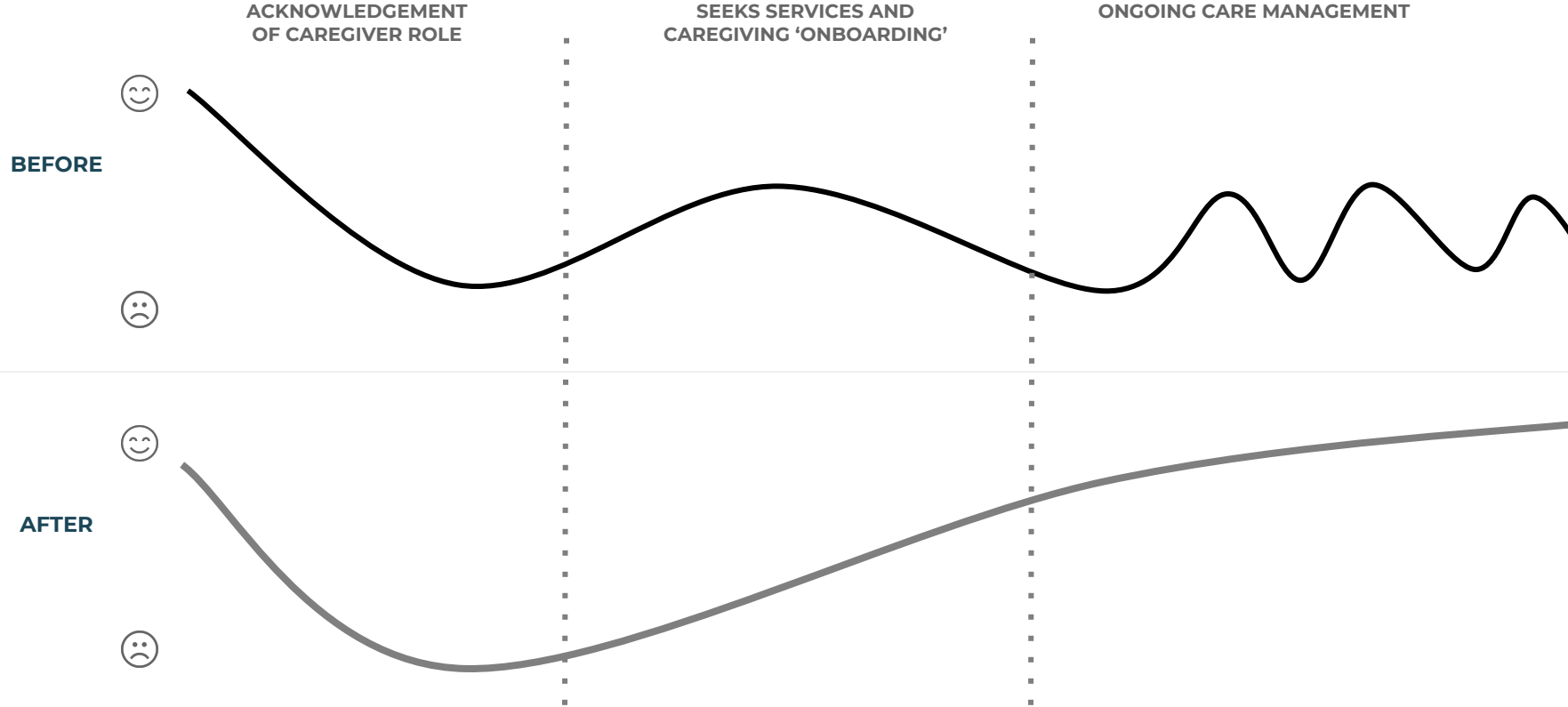Wilis, Jeanette   CONNECT WITH VA

MEETING CAREGIVER NEEDS

The caregiver portal concept meets critical user needs.

NEED	CAREGIVER ID	CAREGIVER PROFILE	MESSAGING	RESOURCES	COORDINATOR INTEGRATION	WELCOMING UI	CLEAR LANGUAGE
		PORTAL FEATURES			DESIGN CONSIDERATIONS		
Understand Caregiver Role			●		●		●
Recognition and Compassion from VA	●		●	●	●	●	
Access Care Efficiently for Veteran	●	●		●		●	
Access Care for Self	●	●			●	●	
Communicate Easily with VA and VISN		●		●	●		●

CAREGIVER JOURNEY

ACKNOWLEDGEMENT OF CAREGIVER ROLE

SEEKS SERVICES AND CAREGIVING 'ONBOARDING'

ONGOING CARE MANAGEMENT

BEFORE

AFTER

"

INCONSISTENCY

"What we find in our experiences – a lot of inconsistencies across VAs, across caregiver support coordinators. **Inconsistencies in just getting your veteran benefits.**"

LISA,
ENGAGED
CAREGIVER FOR US
ARMY VETERAN

"

JUDGMENT

"**When we ask for assistance or help, they look at us and pass judgment.** We get negated. People with physical injuries get a ton of attention, but when we can ask for something, we are denied"

ASHLEY,
EXPERIENCED
CAREGIVER FOR AIR
FORCE VETERAN

"

FEEDBACK

EMPATHY

"**I love this!** If we could have a dedicated channel where the caregiver and coordinator could communicate, that would be incredibly valuable. **I have to go to them for everything, they never come to me**, it would be nice to have something they could easily share."

MARGARET,
ENGAGED
CAREGIVER FOR
IRAQ WAR VETERAN

"

FEEDBACK

FREEDOM

"**Being able to pull up something like this myself would be very handy**, with your own appointments...I like the idea of the caregiver coordinators, some of them have so many caregivers, having this snapshot they could review before they have contact."

ASHLEY,
EXPERIENCED
CAREGIVER FOR
AFGHANISTAN WAR
VETERAN

Considerations & Implementation

FUNCTIONAL CRITERIA

Criteria for evaluating and framing the effectiveness of a caregiver portal.

	DESIRABILITY	TECHNICAL FEASIBILITY	RESOURCING
CRITERIA	Relevant Helpful Likelihood of use Likelihood of recommendation	Individual Institutional System: adherence to existing policies, processes, relationships	Limited requirement for "new" resources Limited cost & team Ease access to the right services
DESIGN PRINCIPLES	**Secure** **Non-judgmental** **Responsive** **Personalized** **Low-maintenance** **Accessible** **Authentic**	**Low-maintenance** **Integrated** **Agile** **Open Source**	**Adaptable**

PORTAL: ROLLOUT PLAN

The following rollout plan describes the recommended structure for implementing and executing the VA caregiver portal.

2018

2019
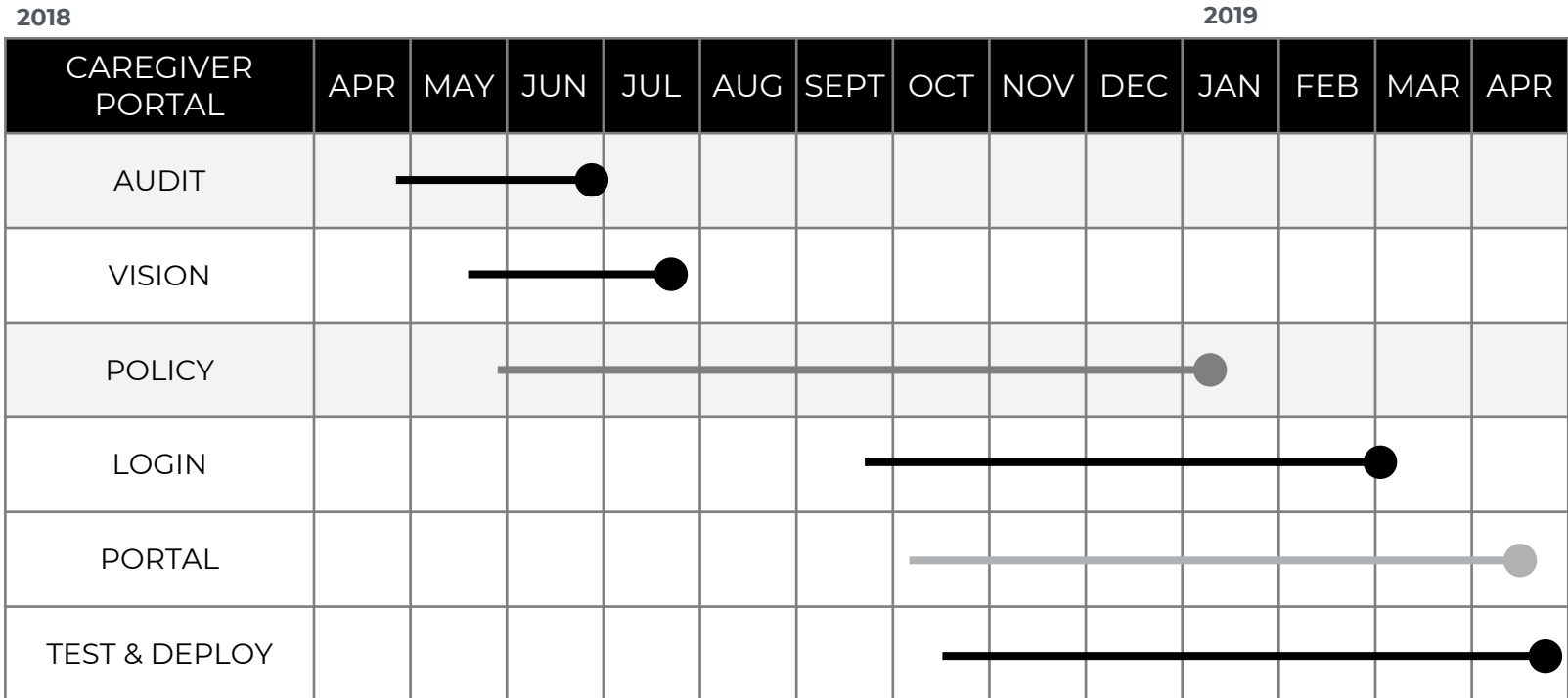
CAREGIVER PORTAL	APR	MAY	JUN	JUL	AUG	SEPT	OCT	NOV	DEC	JAN	FEB	MAR	APR
AUDIT		●━━━━━━━━●											
VISION			●━━━━━━━━●										
POLICY			●━━━━━━━━━━━━━━━━━━━━━━●						●				
LOGIN							●━━━━━━━━━━━━━━━━━━●						
PORTAL								●━━━━━━━━━━━━━━━━━━━━━━━━━●					
TEST & DEPLOY								●━━━━━━━━━━━━━━━━━━━━━━━━━━━●					

SO WHAT?

- Build a **portal** to improve caregiver care and reduce risk

- Architect a **measurable** caregiver population

- Create **consistency** across VA Centers

- **Personalize** the system for the caregiver

- **Bridge** eras and technology skill, while increase utility of existing caregiver programs

JEANETTE

Recognized and ready

Manages personal time and care

Discovered new resources

Connects to coordinator
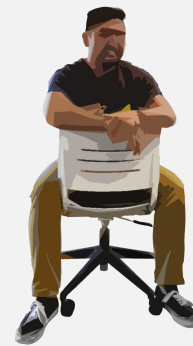
BRYCE

Confident and connected

Manage new identity as caregiver

Relationship with coordinator

Telehealth and remote guidance

Thank you

Appendix

DIAGNOSIS

PROBLEM

CAREGIVER
Lack of recognition, lack of consistency...

...RESULTS in frustration,
confusion, lack of support

COORDINATOR
Lack of simplified communication, barriers to
facilitating care...

...RESULTS in frustration,
administrative burden

DIAGNOSIS

SOLUTION?

PROBLEM

CAREGIVER

- ⟩ **NO FORMAL ONBOARDING**
- ⟩ **LIMITED SOCIAL SUPPORT**
- ⟩ **VETERAN FIRST MINDSET**
- ⟩ **SEEKING "NORMAL"**

SOLUTION

CAREGIVER + COORDINATOR

- ⟩ **ACCESS SUPPORT**
- ⟩ **STREAMLINE COMMUNICATION**
- ⟩ **SECURE RECOGNITION**
- ⟩ **EMPOWER DIGITALLY**
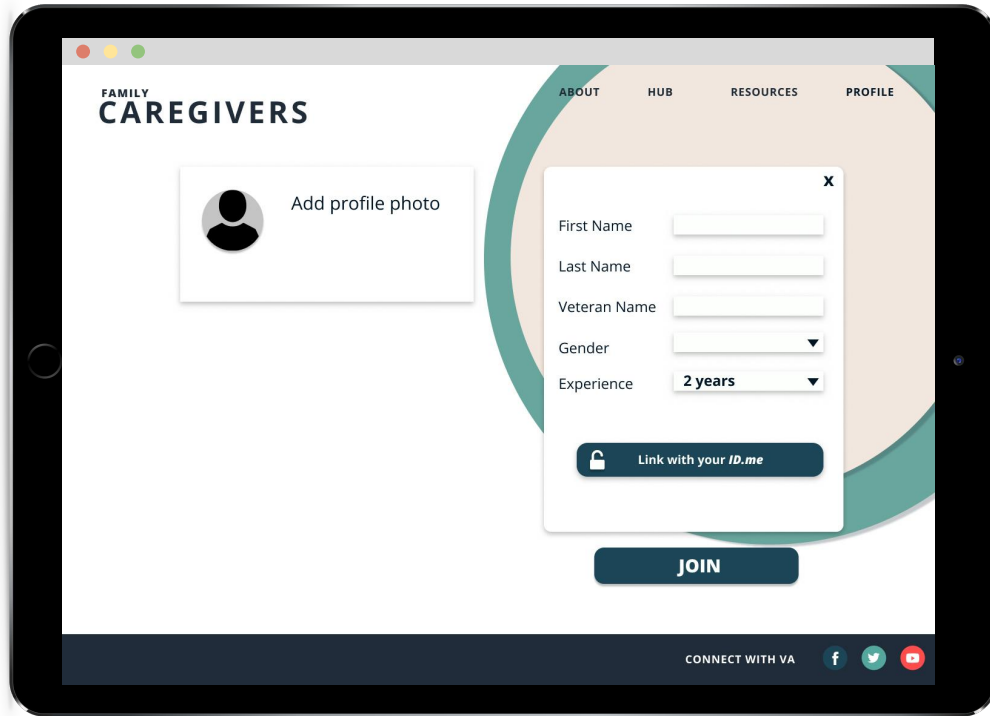
CONCEPT

VA CAREGIVER PORTAL

A portal that unites four key features to address caregivers' needs in their journeys:

"

FEEDBACK

ACTION

"Caregivers will feel 'they don't have anything for me if I'm a caregiver and I'm not getting a stipend.' **This is a way to step up their game** because they're doing something for you."

ASHLEY,
EXPERIENCED
CAREGIVER FOR
AFGHANISTAN WAR
VETERAN

"

FEEDBACK

HARMONY

"It's important for **caregiver coordinators** to understand the caregivers they work for, they need to be more in tune with how much they do, what their needs are."

OREN, FATHER TO A
LEGALLY BLIND IRAQ
CONFLICT VETERAN

TECHNICAL FEASIBILITY

How feasible is this portal given the current tools and systems across the U.S. Department of Veterans Affairs, Veteran Service Organizations and continuums of care?

INDIVIDUAL
Integrates with existing Caregiver Assessment Tool (CAT) and Care-T system.
Reduces and/or stabilizes overall caseload.

INSTITUTIONAL
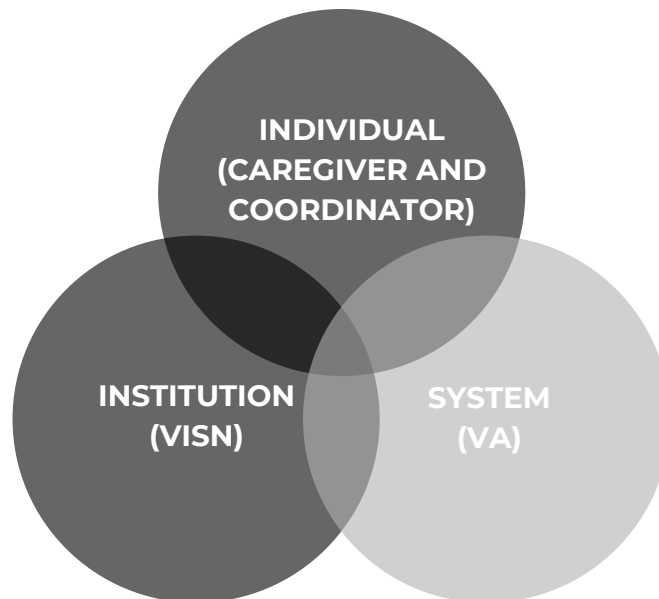Integrates with existing case management systems and scheduling processes.
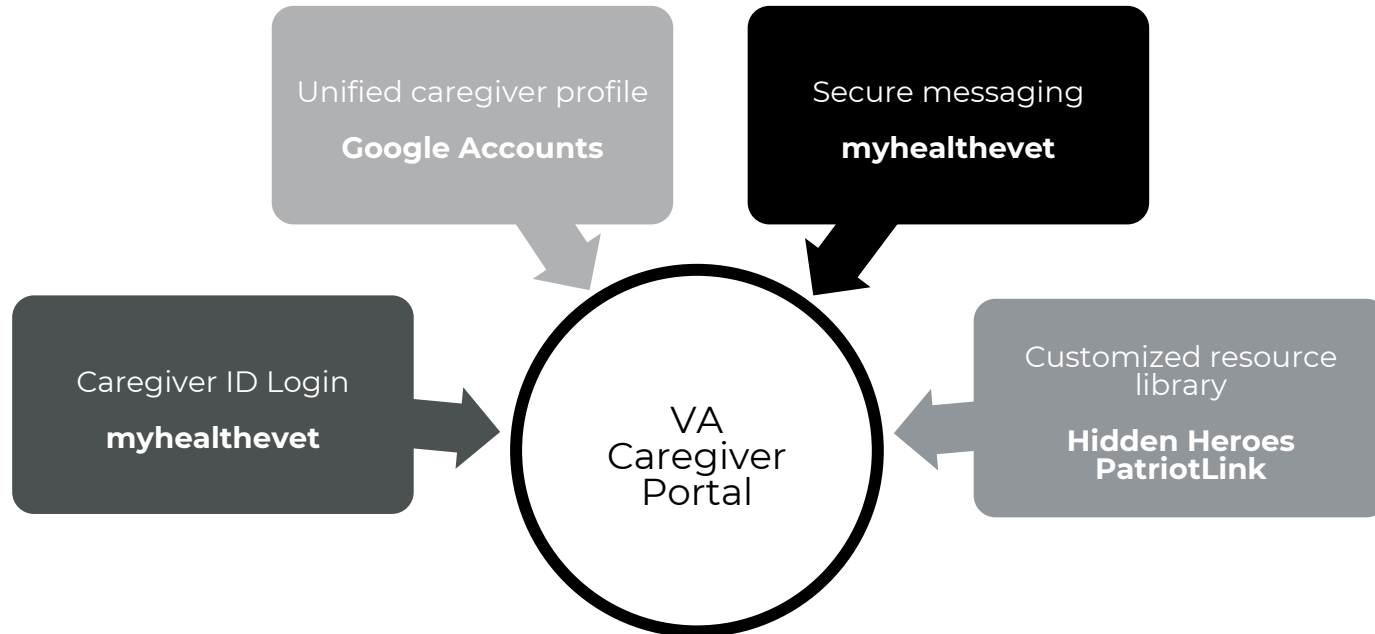Aligns with district norms.

SYSTEM
Hosted at Vets.gov and integrated with ID.me / Veteran ID & Veteran experience team.
References existing caregiver resources provided through VA.gov and third parties.

INDIVIDUAL (CAREGIVER AND COORDINATOR)

INSTITUTION (VISN)

SYSTEM (VA)

LOOKALIKE SERVICE MODELS

Existing digital assets that prove the viability of caregiver portal features.

Unified caregiver profile
Google Accounts

Secure messaging
myhealthevet

Caregiver ID Login
myhealthevet

VA Caregiver Portal

Customized resource library
Hidden Heroes PatriotLink

LOOKALIKE SERVICE MODELS

Existing digital assets that prove the viability of caregiver portal features.

**FEATURE:
LOGIN**

Centralized login and
dedicated identity

myhealthevet

MANAGEMENT

**FEATURE:
PROFILE**

Clarity in security and
privacy

Clear links for controlling
personal information

Google

SECURITY

**FEATURE:
MESSAGING**

Secure messaging with
explicit HIPAA
compliance

myhealthevet

OWNERSHIP

**FEATURE:
RESOURCES**

Keyword search

Eligibility, validation, and
approved programs

Hidden Heroes

CLARITY

RESOURCING

What inputs are required to establish and manage this system? How should VA execute?

SETUP	MANAGEMENT	EFFICIENCY
UX and UI (2 FTE)		Increase data-driven national caregiver administration
Technical Researcher (1 FTE)	Program Manager (1 FTE)	Reduce need for face-to-face, phone interaction
Project/Program Manager (1 FTE)	Technical Management (1 FTE)	Reduce caregiver error
Procurement	Resources Moderator (0.5 FTE)	Increase program compliance & caregiver skill
Security		Alleviate coordinator burden, reducing turnover
Systems Integration		

Execution

PORTAL: NEXT STEPS

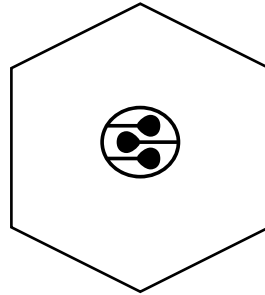Guide to the implementation and development of the caregiver portal.
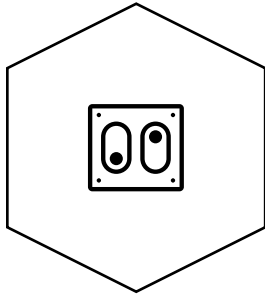
FEATURES

Deploy VA.gov, caregiver community, and Vets.gov survey instrument to develop quantification for caregiver identification.
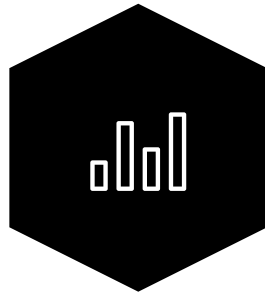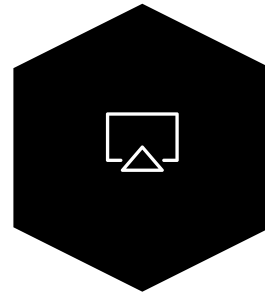
BENCHMARK

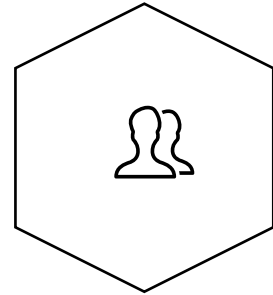Plan and launch caregiver census to measure caregiver community needs.

ALIGNMENT

Align with existing VA strategic efforts including mapping the Veteran and caregiver's experiences.

USER PANEL

Recruit and launch caregiver user board to deliver feedback regarding their own, and Veteran, experience and needs, and down the line, the initial MVP.

PARTNERS

Identify and recruit technical team and Veteran Service Organization stakeholders to serve as contributing partners.