



U.S. Department
of Veterans Affairs



DIGITAL SERVICE at VA

Team VA Caregivers
User Insights Presentation
Friday, 09 March 2018

How might we...
enable VA and DSVA to
better support family
caregivers in meeting their
complex needs?

What is a family caregiver?

A family caregiver is any supporter who plays a role in managing care for any Veteran who requires assistance due to the presence of visible and invisible wounds

5.5m

There are approximately **5.5m caregivers** across the United States caring for wounded service members or veterans

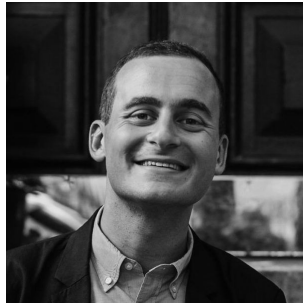
Our team



**Amelia
Sampat**
HKS '18



**Dani
Cinali**
HKS '19
Tuck '19



**Matt
Spector**
HKS '18

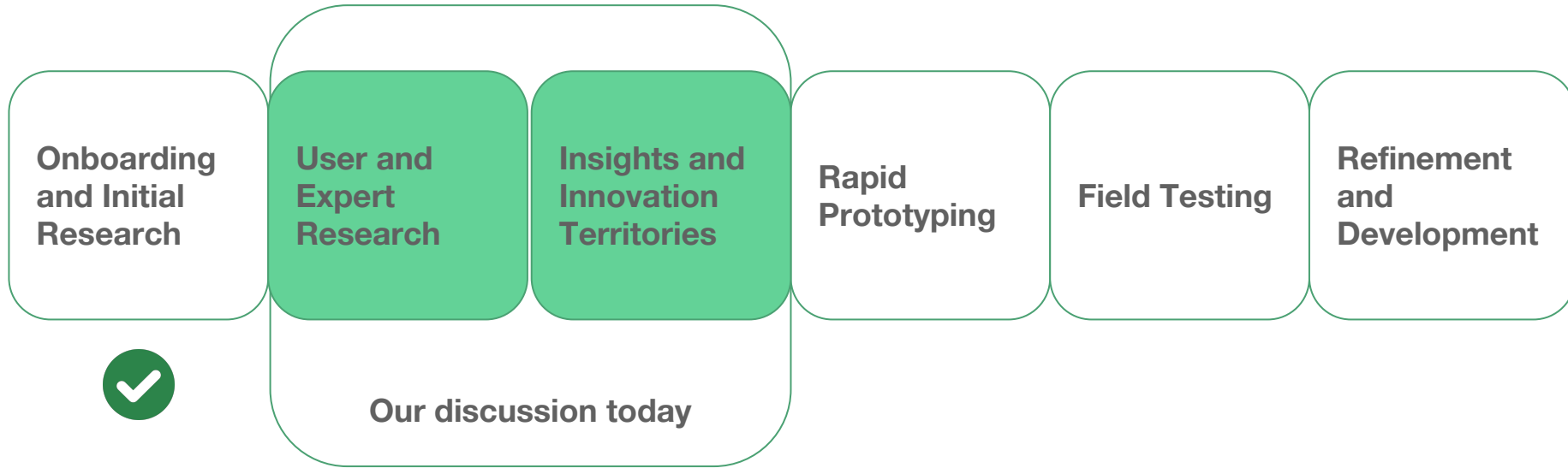


**Brandon
Lee**
College '19



**Kate
Spies**
SEAS '19
GSD '19

Project timeline



Overview

- Methodology
- Expert Findings
- User Journey and Findings
- Personas
- Key Insights and Areas of Opportunity
- Next Steps

Overview

- **Methodology**
- Expert Findings
- User Journey and Findings
- Personas
- Key Insights and Areas of Opportunity
- Next Steps

Methodology Summary

Method

Literature Review

Caregiver Interviews

Veteran Interviews

Expert Interviews

Site Visits

How

18+ databases and academic studies

25 interviews with part- and full-time caregivers

10+ Veteran interviews, service across 4 branches

12 expert interviews

2 visits to Boston Vet Center & West Roxbury VA Hospital



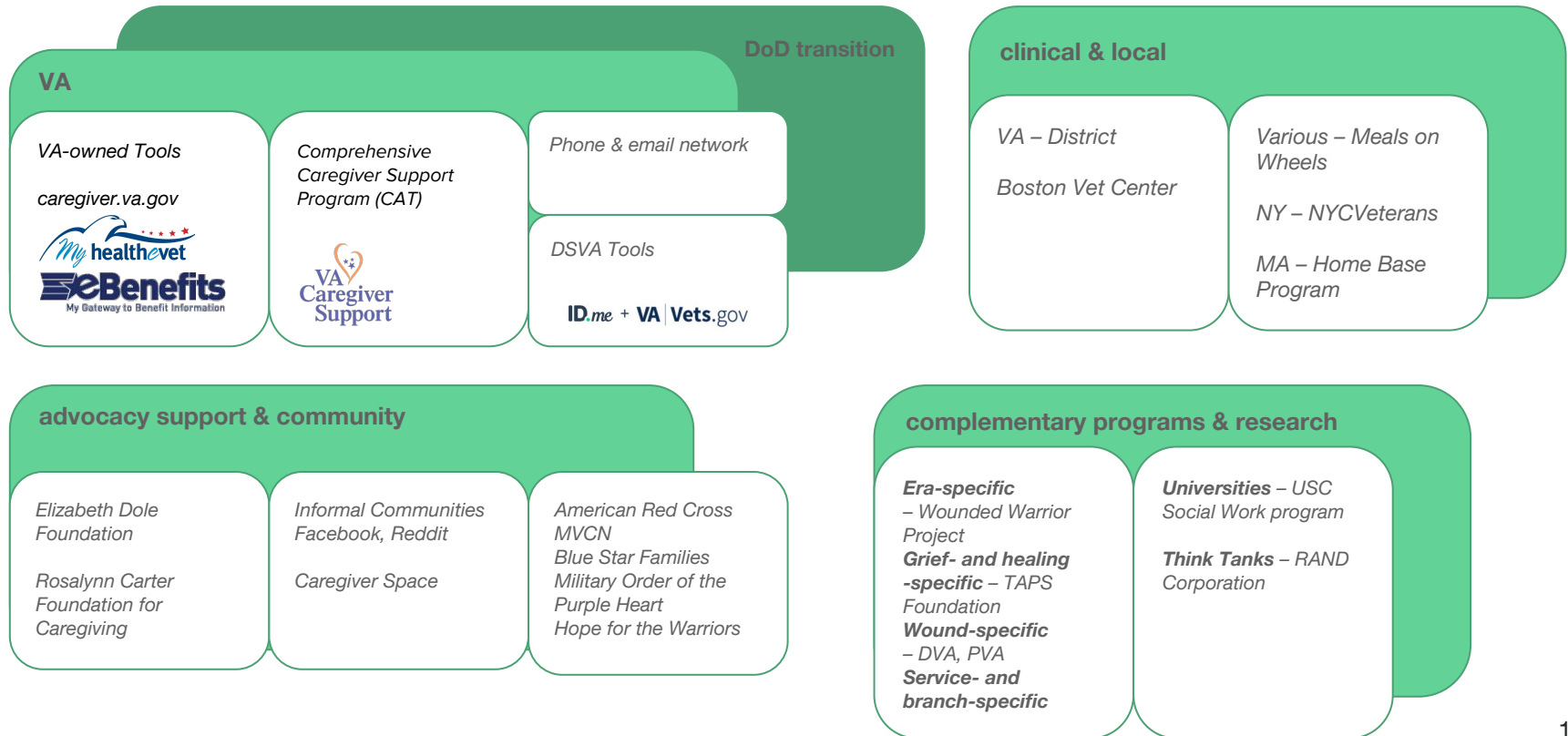
Insights Summary

- 1 The caregiver support system is vast and complex, contributing to systemic challenges including limited access to services and support.
- 2 Caregivers don't acknowledge their role until they need help the most – only to find they must acclimate with little initial support or guidance.
- 3 Local and social media networks not only fill in the gaps around guidance and training, but are critical sources of emotional support.
- 4 Caregivers put the Veteran first, absorbing the Veteran's pain while silently struggling and deprioritizing time for themselves.
- 5 Caregivers strive for normalcy but grapple with the extent of caregiving demands, the unpredictability of their schedules, and anxiety over leaving the Veteran alone.

Overview

- Methodology
- **Expert Findings**
- User Journey and Findings
- Personas
- Key Insights and Areas of Opportunity
- Next Steps

Caregiver support system is vast and complex



Other Systemic Challenges

Transition from DOD to VA	Stipend program	Connected care	Data	Caregiver medical care	Systemic adaptation	Privacy
<p>Inconsistent outreach to caregivers</p> <p>No formal training provided to caregivers</p>	<p>Strict eligibility creates unnecessary division among caregivers</p>	<p>Lack of coordination across complex medical needs</p> <p>VA case coordinators overburdened</p>	<p>Lack of data and information around true number of caregivers</p>	<p>Gap in medical care for caregivers' secondary trauma</p>	<p>VA lags behind modern approaches (online, mobile, telehealth)</p>	<p>Veteran and caregiver have privacy trust issues</p>

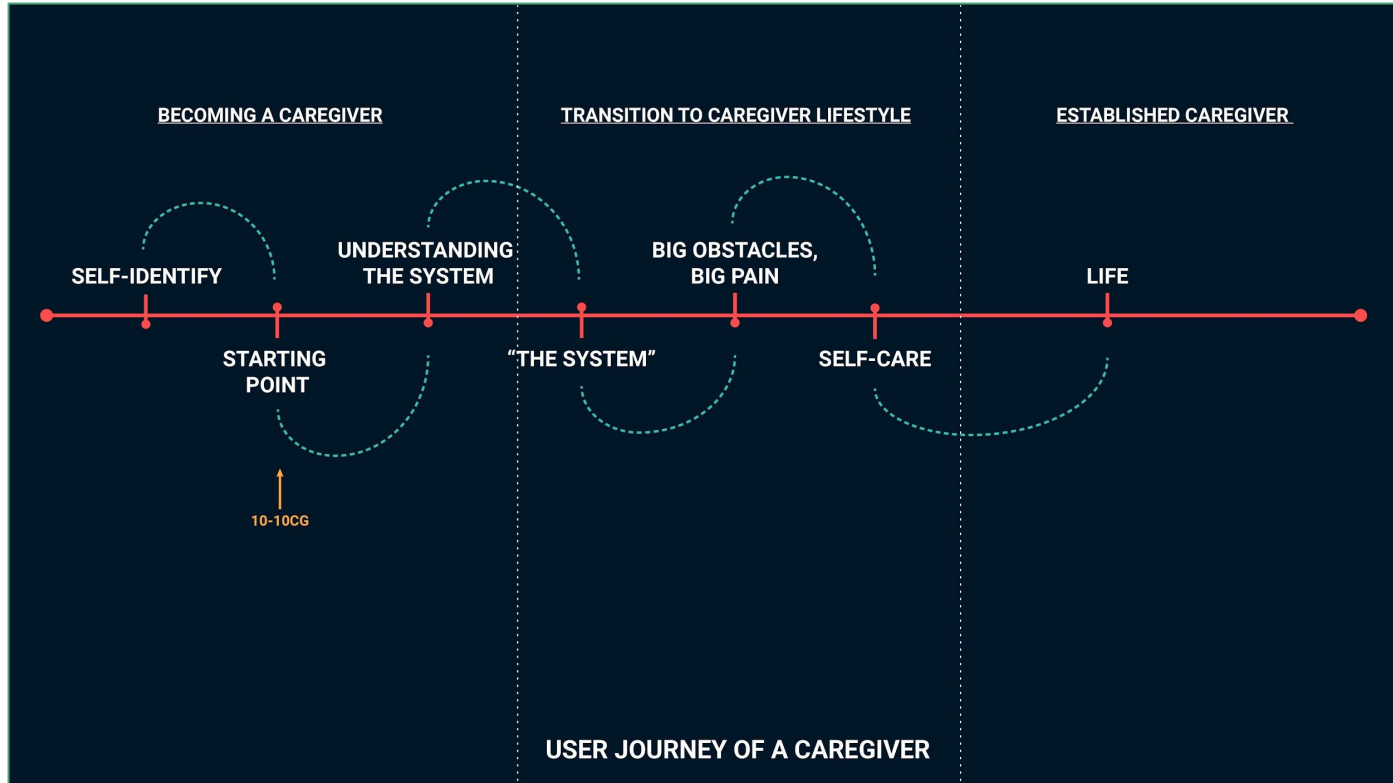
Overview

- Methodology
- Expert Findings
- **User Journey and Findings**
- Personas
- Key Insights and Areas of Opportunity
- Next Steps

User Journey



User Journey At-A-Glance












CAREGIVER JOURNEY

BECOMING A CAREGIVER

TRANSITION TO CAREGIVER LIFESTYLE

ESTABLISHED CAREGIVER

SELF-IDENTIFY	STARTING POINT	UNDERSTANDING THE SYSTEM	"THE SYSTEM"	BIG OBSTACLES, BIG PAIN	SELF-CARE	LIFE		
I feel confused.	I feel overwhelmed.	I feel like I can't win.	I feel like I've got the hang of it.	I feel lost.	I feel conflicted.	I feel stressed.	I feel stretched thin.	I feel helpful and needed.
Am I a caregiver? Dramatic event Change in relationship with Veteran Title given	Who should I speak with? Inexperienced Untrained Do I qualify? What services are available?	VA vs Military Veteran care options reduced/different Little outreach Informal rules	Navigating Norms Confusing admin Will I remain eligible? Poor service Difficult to harmonize care	Move to support Veteran care Job status change Need a community that understands Veterans Veteran condition fluctuates Is this my life now?	Balance! What is my purpose? Self-care moments Need my own time Worry about Veteran during personal time	<u>Finances</u> Work part-time Constraints/limits	<u>Managing a schedule</u> Kid and Veteran care Appointments Household duties + care Missing events	<u>Providing care</u> Stretches for Veteran Home arrangement Veteran stimulation Real conversation
Delayed engagement Google "caregiving" Ask health professional Talk to family/friends Keep Veteran issues hidden Try to return to the "old way?" 	Take time off of work Rearrange home Adjust personal schedule Download apps Read caregiving blogs VA appointments Fill out 10-10CG 	Ask friends/professionals direct questions Connect DOD to VA Deep dive into resources VA website research Write down the new words Enroll in digital system 	Learn rules in order to avoid being dropped Call for appointments Call on administration Call to change appointments Drive to/from appointments Logistics 	Organize move Quit job / stop working Look for new community Power of Attorney Harness courage Reach out on blogs 	Establish morning routine Schedule respite Ask family to help Create opportunities for personal time Start part-time work 	Balance budget Make cuts Adjust lifestyle for new financial limitations 	Coordinate with VA Coordinate with kids' schools Establish routine for Veteran Remain flexible Maintain traditions Establish priorities 	Take training Relationship/Caregiving divide - ON/OFF Read blogs for tips Attend group therapy Avoid Veteran triggers 

DESIGN CONCEPTS

Overview

- Methodology
- Expert Findings
- User Journey and Findings
- **Personas**
- Key Insights and Areas of Opportunity
- Next Steps

user personas

our profiling dimensions:

- caregiver relationship to Veteran
- caregiving need of the Veteran (assessment method: degree and nature of Veteran injury)
- Veteran's access to care (assessment method: proximity to in-person care; mobile and telehealth access; care eligibility)
- caregiver's need for engagement (assessment method: degrees of independence, activity, respite desired)
- caregiver technology skill

Melanie, the On-the-Go Caregiver

Part-time Education Administrator, Parent, Spouse and Caregiver to a Disabled Veteran



Caregiver Details

- Spouse
- Mother
- Part-time job
- Uses iPad, Alexa
- Role realization after PTSD episode

Needs

- Respite
- Understanding from the community
- Reduced burden of scheduling appointments

Relationship to Veteran SPOUSE

Veteran's Need for Caregiver



Veteran's Access to Care



Caregiver's Need for Engagement



Technology Skill



Meet Paula, the Self-Motivated Caregiver

PhD Candidate, Mother and Caregiver to a Disabled Veteran



Caregiver Details

- Mother to disabled veteran
- Lost job
- Pursuing advanced degrees
- Family readiness coordinator
- Feels lonely and isolated

Needs

- Flexible employment
- Clinical counseling through psychological services

Relationship to Veteran PARENT

Veteran's Need for Caregiver



Veteran's Access to Care



Caregiver's Need for Engagement



Technology Skill



Meet Ashleigh, the Engaged Caregiver

Former Professor and Small Business Owner, Parent, Spouse to a Disabled Veteran



Caregiver Details

- Lives in rural area
- Former professor at a local college
- Successful small business owner
- Full-time caregiver to son
- Moved to access higher-quality VA
- Runs caregiving community
- Part-time employment as organizer

Needs

- Respite, not as vacation but as a cup of coffee or an hour off
- Better understanding of the challenges of TBI from VA and healthcare system
- Digital reminders for Veteran care

Relationship to Veteran PARENT, SPOUSE

Veteran's Need for Caregiver



Veteran's Access to Care



Caregiver's Need for Engagement



Technology Skill



Meet Billy, the Veteran Caregiver

Active Duty Military and Veteran



Caregiver Details

- Active-duty Marine Corps
- Joint-caregiver for a wounded warrior from his regiment
- Helps with errands on the weekends

Needs

- Feeling more equipped to assist in providing care
- Understanding the support team and services available for the Veteran
- Identifying what more they could/should be doing for the Veteran

Relationship to Veteran FRIEND, NEIGHBOR

Veteran's Need for Caregiver



Veteran's Access to Care



Caregiver's Need for Engagement



Technology Skill



Overview

- Methodology
- Expert Findings
- User Journey and Findings
- Personas
- **Key Insights and Areas of Opportunity**
- Next Steps

1

**Caregivers don't
acknowledge their role
until they need help the
most – only to find they
must acclimate with little
initial support or
guidance.**

“One of the ways I found out I was a true caregiver, in 2009 in middle of the night I was picked up and thrown across the room.”

“The Army didn't tell me anything. They didn't tell me about his PTSD or TBI. He had been in six explosions...I had no idea how to deal with his rage...self-medicating with alcohol.”

“The VA told me, ‘we don't have space for you, we [only] just started dealing with the Vietnam veterans.’”

“I was often asked, ‘he doesn't need help, so why are you here?’”

2

Local and social media networks not only fill in the gaps around guidance and training, but are critical sources of emotional support.

“The venting is useful but it's the solidarity of identity that is most useful about [family caregiver] networks.”

“These networks help me focus on trying to stay resilient, living life with gratitude...”

“The civilian world doesn't get it. They don't understand where we're coming from, and I'd rather have someone who knows what I'm going through to open up with.”

3

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

“I constantly needed to be on my game, to document everything and be very aware that this was a battle sometimes between getting VA help and services for my daughter.”

“It’s insulting to hear the VA tell me I need to take time for myself when they could get rid of wait times.”

“He gets frustrated – he gets angry, he doesn’t mean to do it, he takes his anger out on anything that’s around him, an hour later he doesn’t remember.”

4

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

“I was teaching psychology at a local college...that was my me time, that was my get away escape time, and I had to cut back, I had to give that up for his care.”

“I am constantly on call for my husband's suicide watch – I am never off my job.”

“It is difficult to be a lover or a spouse while being a caregiver, which is a motherly role. Sometimes my husband will tell me to stop being so motherly.”

Areas of prototyping and exploration

Prioritizing four key prototyping areas informed by our insights:

1. Understanding the caregiver role & becoming a caregiver



Caregiver acclimation

Potential prototypes:
“getting started” tools,
military and
caregiver vocabularies,
customized, on-demand
training

2. Cultivating social sources of support



Caregiver connection

Potential prototypes:
connections to peers,
connections to assistance,
bridges to outside
organizations

3. Deprioritizing self-care and identity



Caregiver routine

Potential prototypes:
mental health support,
support for children,
respite care

4. Managing the unpredictable



Caregiver independence

Potential prototypes:
micro-work,
leadership and
self-improvement,
improved benefit allocation
and review

Focus on
caregiving

Focus on
caregiver

Overview

- Methodology
- Expert Findings
- User Journey and Findings
- Personas
- Key Insights and Areas of Opportunity
- **Next Steps**

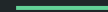
So what?

Caregivers need more, and we owe them a shift in perception.

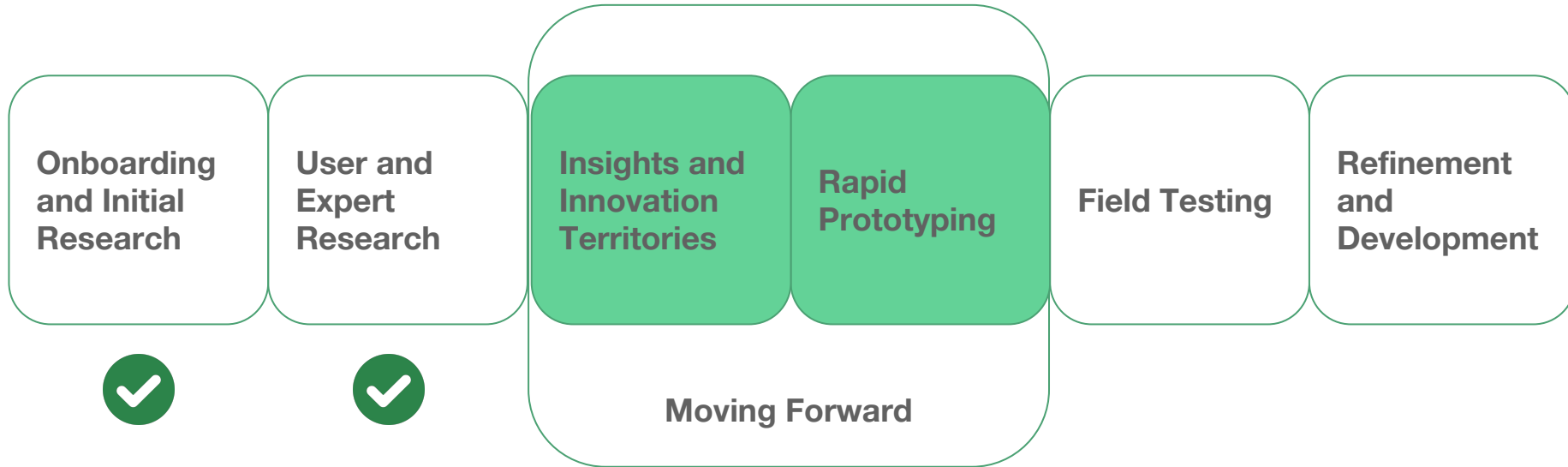
Resources are scattered.

A distributed and fragmented identity, needing on-demand and often customized interventions.

They believe digital interventions can improve their lives.



Project timeline



Team VA Caregivers Design principles

Our key design principles for prototyping and advancing insights into action:

- **Secure**
- **Non-judgemental**
- **Responsive**
- **Personalized**
- **Low-maintenance**
- **Adaptable**
- **Accessible**
- **Authentic**

Thank you.



DIGITAL SERVICE at VA

Methodology | Detailed

Method

Literature Review

Caregiver Interviews

Veteran Interviews

Expert Interviews

Site Visits

Why

- Understand academic findings regarding Veteran caregiver interests, existing programs, and best practices
- Speak directly to end users
- Assess a variety of caregiver experiences, challenges, needs, programs, interactions with VA, and current uses of digital tools
- Understand Veteran norms and needs
- Understand interaction with VA medical system
- Understand system-wide coordination, programs, and macro trends in caregiver space
- Understand staff and expert workload and barriers
- Understand Veteran and caregiver experience from staff perspective

How

- Review of databases and academic studies from VA-supported and non-VA supported research
- **25+** interviews with part- and full-time caregivers
- Direct outreach to caregiver groups and communities (Twitter, Facebook, Reddit)
- Engagement with Dole Fellows
- **10+** Veterans with service across Marine Corps, Army, Air Force, and National Guard
- **12** expert Interviews with VA, RAND Corporation, Dole Foundation, Blue Star Families, NYCVeterans, Home Base, American Red Cross, Caregiver Space
- **2** visits to Boston Vet Center (Boston Seaport) and West Roxbury VA Hospital

Phase 1 | Becoming A Caregiver

day-in-the-life

7:30AM
Getting through the morning

10:30AM
Seeking out help

1PM
Registering for services

4PM
Initial appointments

key pain points

Lack of training, questioning self-identity

Lack of awareness of available services

Confusion/restriction around eligibility; uncertainty around caregiver status

Absorbing information, acclimation to caregiving

programs/VA interaction

Caregiver support line

Personal network, support groups, VA medical center, VA care coordinators

Third party programs, VA care coordinators, external providers

Consultation with VA Hospital and external providers; repeat visits for evaluation + treatment

technology used



ID.me + VA | Vets.gov



Self-identify | Getting started | Understanding the system

Phase 2 | Transition

day-in-the-life

7:30AM
Establishing morning routine

10:30AM
Coordinating household matters

12PM
Coordinating care

4PM
Doctors' appointments

key pain points

Learning life hacks,
balancing household needs

Financial planning,
confronting big changes (e.g.
moving, quitting job)

Securing program benefits,
coordinating healthcare

Ensuring quality care,
mitigating health risks

programs/va interaction

Peer programs

N/A

Comprehensive Caregiver Support Program for Post-911 Veterans, permanent disability status, management of benefits onboarding

Engagement with VA system and providers

technology used



Self-care | Large-scale Obstacles | Navigating the system

Phase 3 | Ongoing Routine

day-in-the-life

4:30AM
Mindfulness Exercises

8:30AM
Day Begins

1:30PM
Staying busy

2:30PM
Manage benefits

9PM
Evening and Sleep

key pain points

Limited time for self-care,
absorb Veteran condition

Conversing, managing
schedules, household duties,
avoid triggers

Limited social or leisure time,
juggling part-time work

Multiple appointments,
medical incidents

Interrupted sleep cycle, lack
of intimacy (spouse)

programs/va interaction

Morning mindfulness, micro-respite

After school drop-off, drives to visit VA
facilities for appointments

Coordination with Dole fellows, manage
caregiver consultation and community

Ongoing benefits management, caregiver
support program reevaluation

technology used



Caregiver Condition | Providing Care | Controlling the Schedule | Finances and Planning | Independence