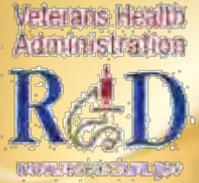


Evidence-based Synthesis Program (ESP)



Mobile and Internet Approaches for Supporting Non-Professional Caregivers: A Systematic Review

Edward Dyer, MD

Devan Kansagara, MD, MCR

Keith McInnes, ScD, Msc

Michele Freeman, MPH

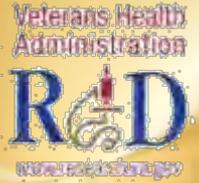
Susan Woods, MD, MPH

Mobile Health at the VA

Kathleen Frisbee MPH PhDc

Neil Evans MD

Evidence-based Synthesis Program (ESP)



Program Overview

- **Sponsored by VA Office of Research & Development, Quality Enhancement Research Initiative (QUERI)**
- **Provide timely and accurate syntheses/reviews of topics identified by VA clinicians, managers and policy-makers, as they work to improve the health and care of Veterans**
- **Builds on staff and expertise of AHRQ Evidence-based Practice Centers (EPC). Four EPCs are ESP Centers:**
 - Durham VA Medical Center
 - VA Greater Los Angeles Health Care System
 - Portland VA Medical Center
 - Minneapolis VA Medical Center.

Evidence-based Synthesis Program (ESP)



- **Provide evidence syntheses on important clinical practice topics relevant to Veterans, and these reports help:**
 - develop clinical policies informed by evidence;
 - Implement effective services to improve patient outcomes and support VA practice guidelines & performance measures;
 - guide the direction for future research to address gaps in clinical knowledge.
- **Broad topic nomination process – e.g. VACO, VISNs, field – facilitated by ESP Coordinating Center (Portland) through online process:**

<http://www.hsrd.research.va.gov/publications/esp/TopicNomination.cfm>

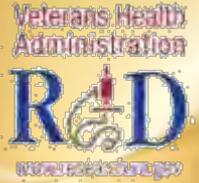
Evidence-based Synthesis Program (ESP)



- **Steering Committee** represents research & operations (PCS, OQP, ONS, VISN), provides oversight and guides program.
- **Technical Expert Panel (TEP)**
 - Recruited for each topic to provide content expertise.
 - Guides topic development; refines the key questions.
 - Reviews data/draft report.
- **External Peer Reviewers & Policy Partners**
 - Reviews and comments on draft report
- **Final reports posted on VA HSR&D website and disseminated widely through the VA.**

<http://www.hsrd.research.va.gov/publications/esp/reports.cfm>

Overview



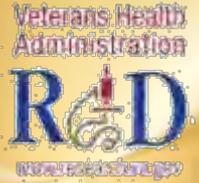
- Introduction – rationale for evidence synthesis
- Systematic review
 - Methods
 - Results
- VA research in health IT
- Clinic in Hand overview
- Questions

Background: Caregivers and Health IT



- **34 to 52 million adults function as caregivers at some point every year**
- **70% to 80% of caregivers seek health information online**
- **26% seek online peer support with other caregivers**

Technology use is rapidly rising



- **In 2010, 78% of US adults had internet access compared to 46% in 2000**
- **Veterans and non-Veterans use the internet at similar rates**
- **Most adults have cell phones (83%)**
 - 77% among those with income < \$30K
 - 56% among those > age 65
 - But only 16% use phone to access internet

VHA is committed to increasing access to consumer health information technologies (CHIT) for caregivers of chronically ill or disabled Veterans

Review Objectives

- **Identify studies of consumer health information technologies designed for non-professional caregivers**
- **Examine usage of CHIT applications**
- **Examine effects on caregiver burden and patient outcomes**
- **Identify gaps in literature**

Key Question 1

How does the use of CHIT by non-professional caregivers of adult patients with chronic illnesses or disability, or by such patients who rely on a non-professional caregiver affect caregiver and patient outcomes?

Key Question 2

What lessons can be learned from studies evaluating CHIT that specifically target the parents/caregivers of children?

Key Question 3

What are the major gaps in the CHIT literature with regards to technology development, availability, and/or evaluation?

Methods: Study Selection



Studies Included:

- **Enrolled non-professional caregivers of adults or children**
- **Reporting caregiver outcomes**
- **Caregiver-facing interactive technology (+/- patient-facing)**
- **No limits based on device or platform**

Methods: Study Selection



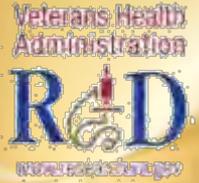
Excluded Studies:

- **Non-interactive technologies (education material or general information)**
- **Involving only telephony, interactive-voice-response, or synchronous telehealth**
- **Using fixed home-monitoring technologies**

Intervention Taxonomy

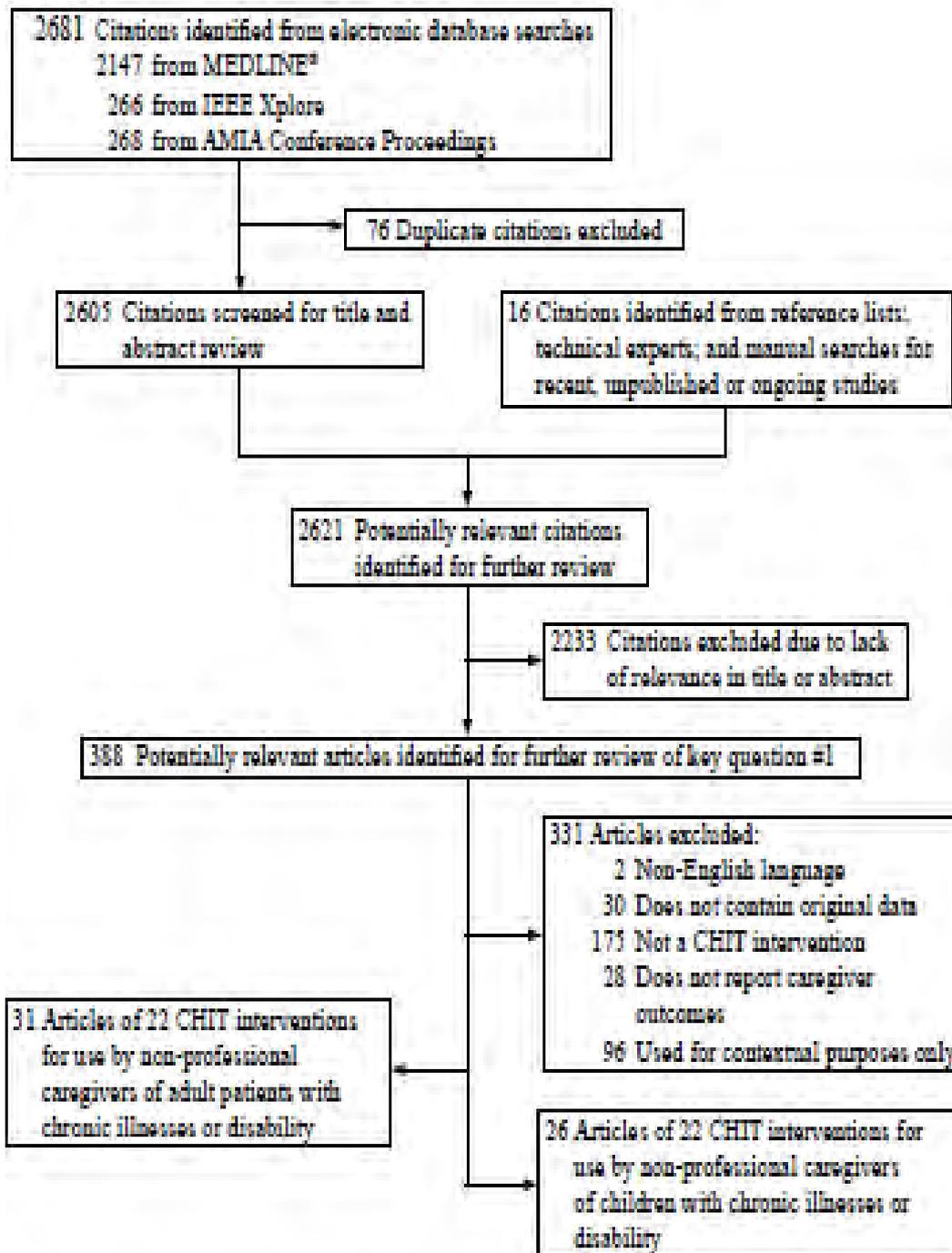
- **Education/skills**
- **Self-care**
- **Peer-to-peer communication**
- **Caregiver-to-professional communication**
- **Patient-to-caregiver communication**
- **Systems transactions**
- **Reminders**

Search



Multiple databases

- MEDLINE, Embase, IEEE Xplore
- AMIA Symposium Proceedings
- Healthcare Information and Management Systems Conferences
- Med 2.0 and Health 2.0

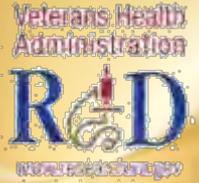


Results: Adult Literature



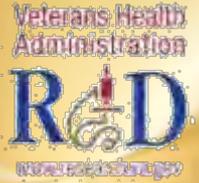
- **31 studies described 22 interventions**
- **Majority offered educational content**
- **Several communication modalities**
 - Online peer support
 - Online access to providers
 - General disease information and education

Results: Adult Literature



- **Small study size, variation in outcomes measured, methodologic weaknesses and diversity of interventions make assessment of health outcome or utilization effects difficult**
- **Some broad themes are apparent**

Impact of Caregiver CHIT



- **Caregiver outcomes: broad variety of metrics, no firm conclusions**
- **Patient outcomes: only 3 studies**
 - Computerlink, Schizophrenia Guide, Dew 2004
- **Care Utilization outcomes**
 - Trend toward reduced admissions in VA (Glynn 2010)
 - Decreased ER visits and admissions (Caring~Web)

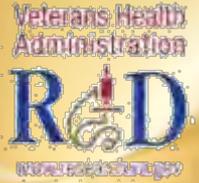
CHES Intervention



Comprehensive Health Enhancement Support System

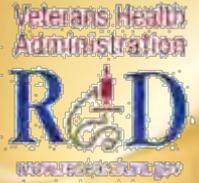
- **Objective: improve lung cancer caregiver coping strategies**
- **Intervention: web peer support, expert care, training.**
- **RCT: n=285, duration 2 years**
 - Enrolled patient-caregiver dyads
 - Controls: received laptop and list of websites.

CHES Intervention: Results



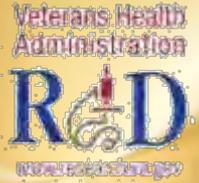
- **Improved coping compared to controls**
 - "Brief Cope" 5-point Likert scale
- **Mediated through bonding measured by sharing feelings, emotional support, etc.**
- **Speculated increased community with formal/closed membership groups, around a common patient condition**

VA intervention: Glynn 2010



- **Objective: Improve patient-caregiver relationship stress in Veterans with schizophrenia**
- **Intervention: web education and scheduled facilitated online support group**
- **Pre-post study for feasibility:**
 - 26 families in intervention group vs. 16 family controls
 - Concern for how to manage emergencies adequately

VA intervention: Glynn 2010



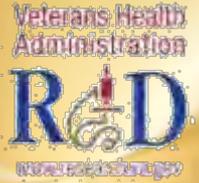
Results:

- Family distress did not change over time nor was different between groups
- Caregiver-patient stress improved over time, but only measured in treatment group
- Trend towards decreased admissions in treatment group

Caregiver's Friend

- **Objective: improve health and stress of caregivers of patients with dementia**
- **Intervention: tailored web education based on a pre-intervention questionnaire**
- **RCT: n=299, duration 30 days**
 - Waitlist controls
 - Average use: 32 minutes but...

Caregiver's Friend



Only 32 minutes resulted in improved (compared to controls), self reported:

- Caregiver self-efficacy,
- Intention to get support,
- Caregiver gain, stress, strain,
- Caregiver depression and anxiety.

Pediatric Caregiver Interventions

Stockwell 2012

- **Objective: increase flu vaccine rates through weekly tailored text messaging**
- **RCT: n = 7,547**
 - Low-income population
- **Vaccine rates improved**
 - 42.6 v 39.9%, $p = 0.001$

Miloh 2009

- **Objective: decrease biopsy-proven rejection in pediatric liver-transplant patients**
- **Pre-post study: n = 41**
- **Intervention: automated text messaging reminding children then parents to take immune meds**
- **Bx-proven rejection improved over one year: 12/41 \rightarrow 2/41, p = 0.02**

General themes

Peer Support

- **Most-used and valued component**
- **Cited benefits:**
 - Convenience of asynchronous communication
 - Access to a greater diversity of experiences
 - Anonymity
 - “Closed” groups may increase a sense of relevance and community compared to “open” such as Yahoo groups, AOL groups.

Peer Support

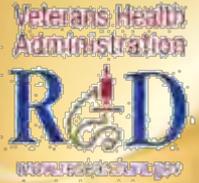
- **Cited challenges:**

- Message threads off-topic
- Not equivalent to face-to-face support
- Inappropriate for some caregivers?
- Caregiver and patient need separate forums

- **Of note:**

- Privacy/security was not a concern for users
- “Flaming” was rare, potentially obviating need for moderators

Online access to experts



- **Benefits reported by caregivers:**
 - Near-immediate availability for questions
 - Increased comfort and empowerment
- **Of note:**
 - Adult-interventions typically used email
 - Pediatric-interventions typically used SMS/texting
 - Expert-care sometimes provided with access to Q&A databases

Generalizability and Usage

- **45% of those approached declined to signup for a CHIT intervention – Chiu 2005**
- **60% attendance at “required” online classes fell to 30% for volunteer sessions – Glynn 2010 (VA study)**
- **9 of 21 families of a child with cancer logged on to CHIT intervention – Ewing 2009**
- **19 of 40 users dropped out – Glueckaulf 2004**

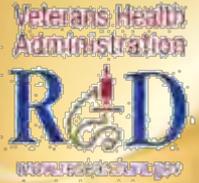
Usage

- **Satisfaction often high among users**
- **Wide variety of usage frequency:**
 - 20x/month – Vehvillainen 2002
 - 1-2 hours/week – Pierce 2009 (Caring~Web)
 - 1x/month by 40% of users – Dew 2004
- **Benefit may occur even with limited use**
 - Beauchamp 2005 (Caregiver's Friend)

User experience

- **Some studies described technical barriers to intervention accessibility**
- **Barriers may be more pronounced in older caregivers**

User experience



CHIT provides opportunity to tailor media to accommodate a diversity of users:

- Vision/hearing/dexterity challenged
- Language barriers
- Attention span (children, ADHD)
- Preferred learning styles (text, audio, video, active)

The amount of technical training necessary for users to optimally use CHIT is unclear.

Gaps in Literature

CHIT is a relatively new field:

- Only 7 studies were designed to evaluate health outcomes.
- Most were in early-development or pilot-testing (15 of 22 interventions).
- Few studies analyzed outcomes separately for caregiver and patient users.

Gaps in Literature

- Few interventions focused on improving patient-caregiver communication
- Few had health system transactions such as Rx refill, request appointment, bill-pay..
- No studies offered contextual understanding of how caregivers use CHIT day-to-day
- No studies evaluated how CHIT complements existing educational and support services

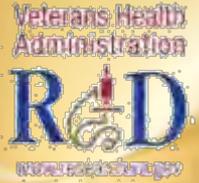
Future directions

- **Involve end-users in design of CHIT**
- **Perform formal usability testing in CHIT implementation**
- **Develop best-practices for technology implementation**
- **Provide peer-peer support groups, access to expert advice, interactive modules**
- **Evaluate caregiver AND patient experiences/outcomes by enrolling dyads**

Limitations

- **Evaluation of CHIT is relatively new and technology is changing quickly**
- **Reviewed technologies targeted at caregivers; technologies targeted at other populations could be adapted**
- **Lack of a common taxonomy for CHIT may have limited search for relevant literature.**

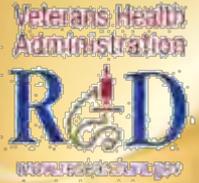
Evidence-based Synthesis Program (ESP)



Full report and cyberseminar presentation is available on ESP website:

<http://www.hsrd.research.va.gov/publications/esp/>

Perspective from a VA researcher



- **“Team sport”**
- **Caregiver burden monitoring**
- **Texting to create 3-way dialog**
- **Caregiving and care-recipient style assessment (CCRAS)**
- **Training**
- **Lessons from ongoing Caregiver Study**



MOBILE HEALTH AT THE U.S. DEPARTMENT OF VETERANS AFFAIRS

OFFICE OF INFORMATICS AND ANALYTICS (OIA) / CONNECTED HEALTH
NEIL C. EVANS, MD AND KATHY FRISBEE, MPH, PhDc- CO-DIRECTORS

FEB. 25, 2013



Connected Health

All Eyes on the Same Information



**Improved
Provider
efficiency**



**Patient
empowerment
through
personalization**



**Enhanced
Collaboration
& Coordination**



**Better Access
through
Improved
communication**

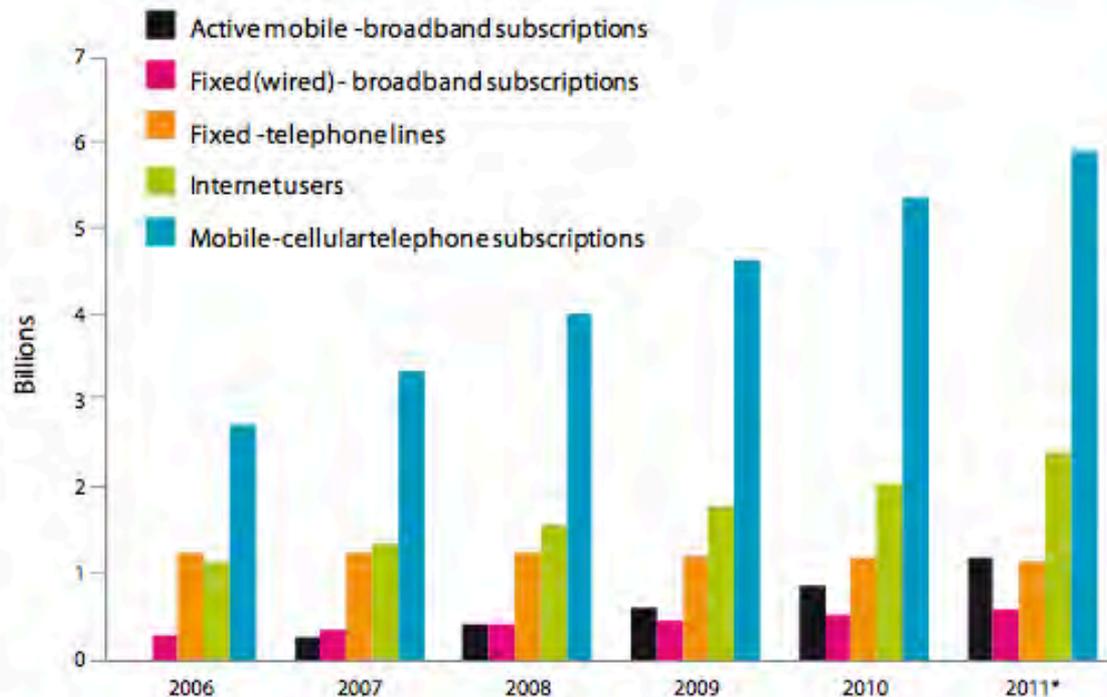


TECHNOLOGY

Technologies Coordinated by Connected Health

- **Mobile Health → Today's Focus**
- TeleHealth
- My HealtheVet (PHR)
- Kiosks
- Patient-Facing Web Applications

Almost 6 billion mobile-cellular subscriptions



- With 5.9 billion mobile-cellular subscriptions, global penetration reaches 87%, and 79% in the developing world.
- Mobile-broadband subscriptions have grown 45% annually over the last four years and today there are twice as many mobile-broadband as fixed-broadband subscriptions

Note: *Estimate

Source: ITU World Telecommunication/ICT Indicators database

Mobile Health Starting to Come of Age



Mobile Devices and U.S. Health Care Providers *Manhattan Research "Taking the Pulse" Survey*

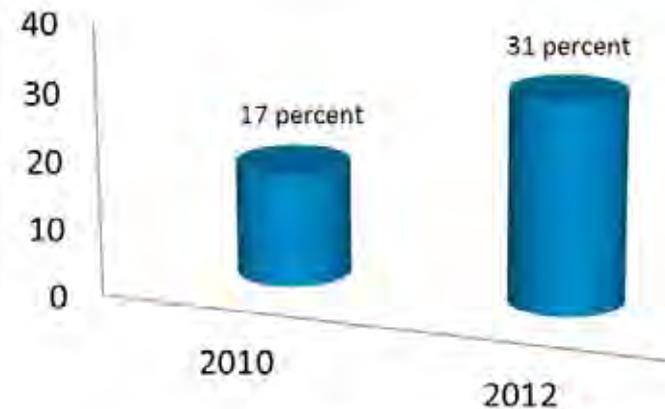
May 2011 (2041 U.S. Physicians)

- 30% owned an iPad
- 28% planned to purchase one in the next six months
- 81% owned a smartphone
- 75% owned at least one Apple product

May 2012 (3015 U.S. Physicians)

- Tablet use up to 62%, as predicted
- 50% of tablet-owning physicians used them at the point-of-care
- Smartphone use remains very high

Percentage of Cell Phone Owners Who Used Their Devices to Look Up Health Information*

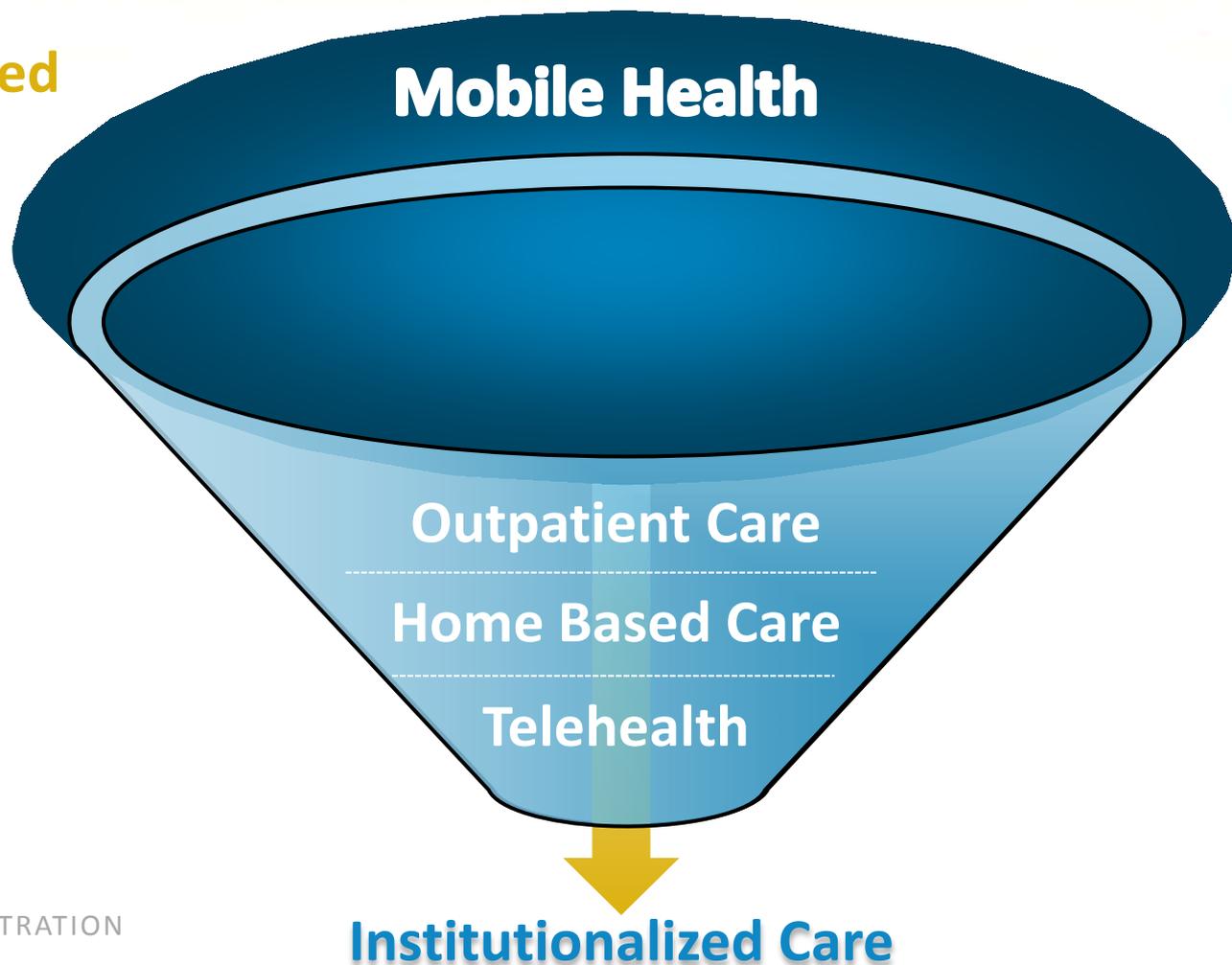
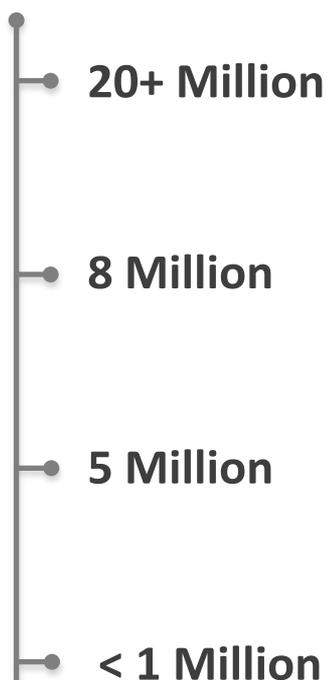


*Pew Internet and American Life Project, November 2012

- Add additional data about Veterans with cell phones

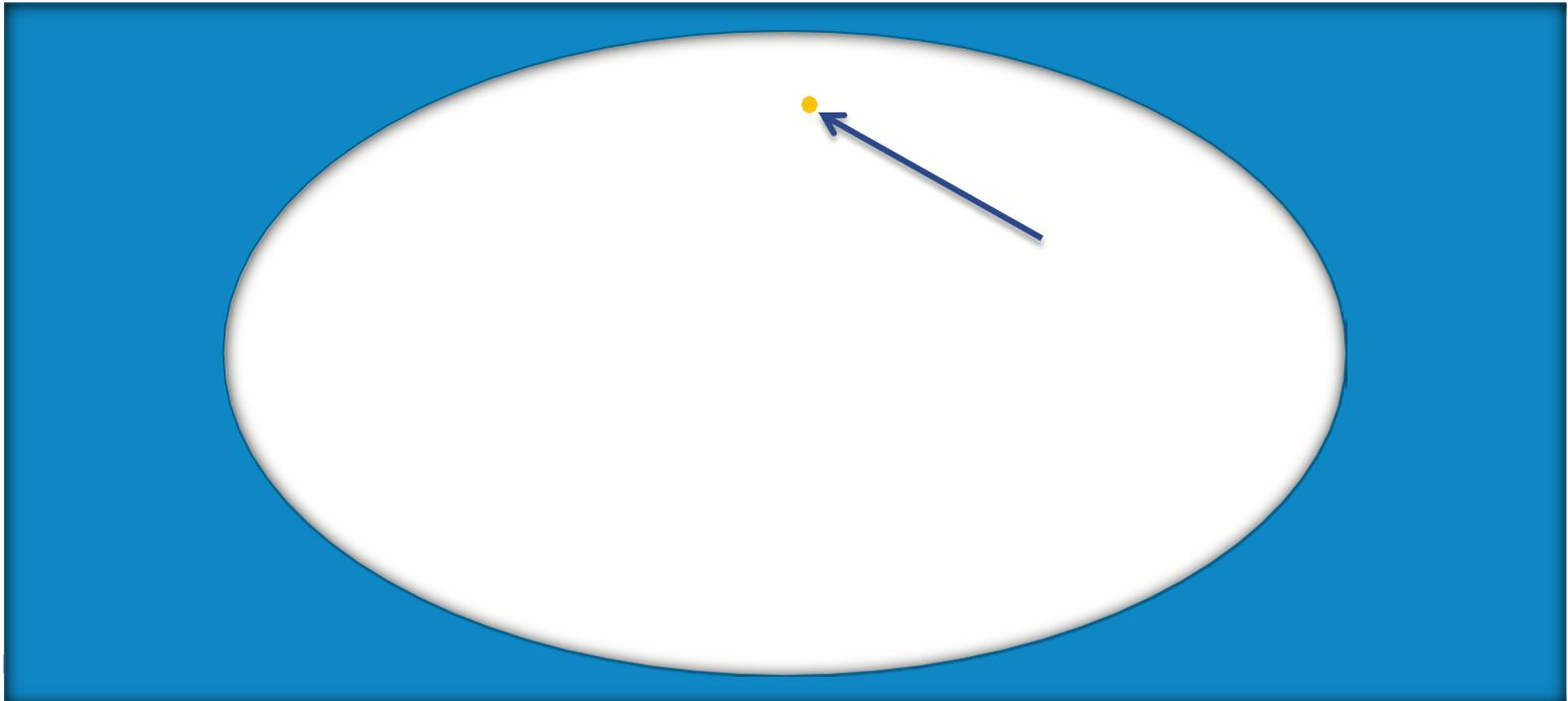
Patient Facing Mobile Health – An Engagement Model of Health Care Delivery, Not A Treatment Model

Veterans Impacted

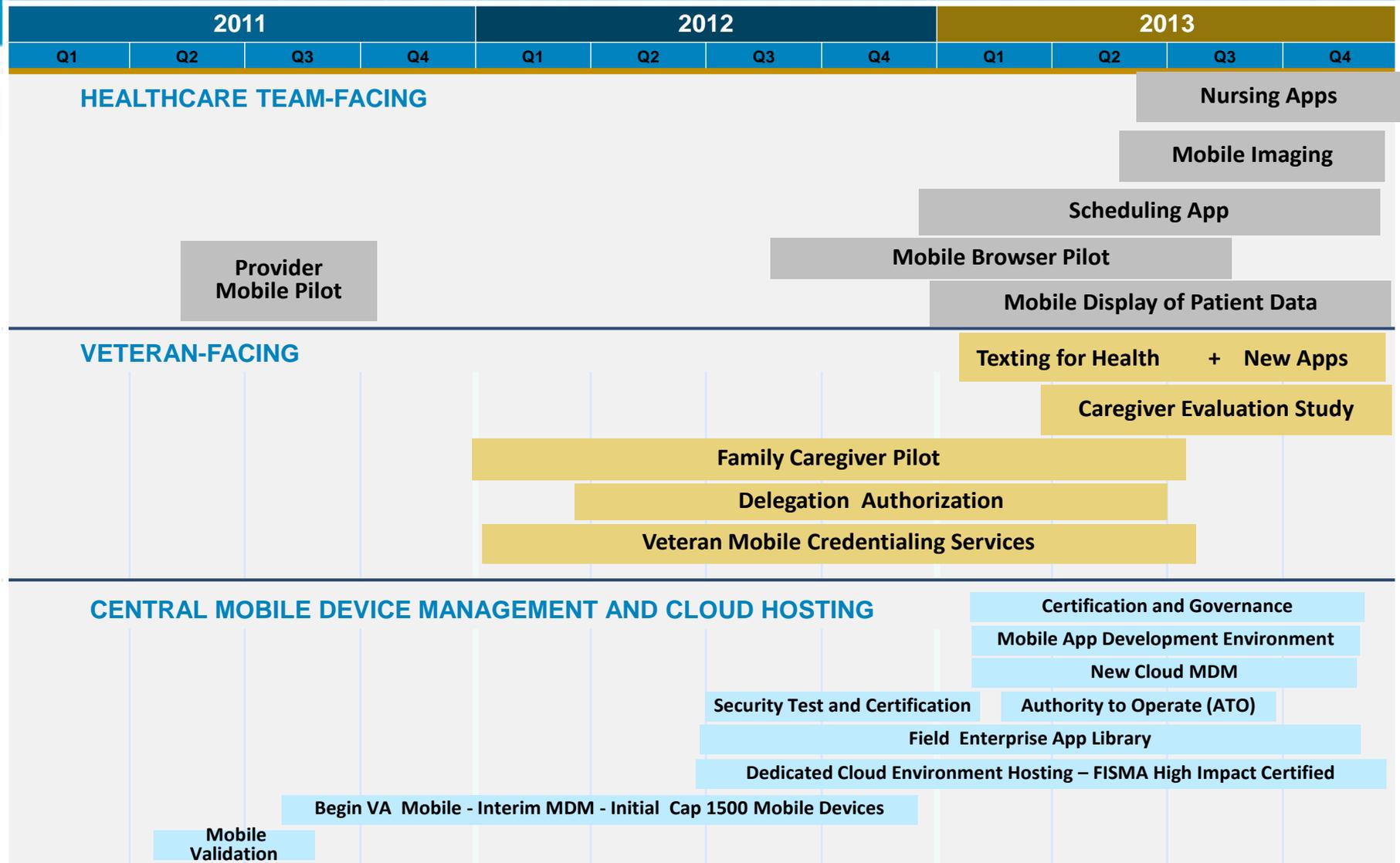


Mobile Health Extending Health Care Beyond Traditional Visits

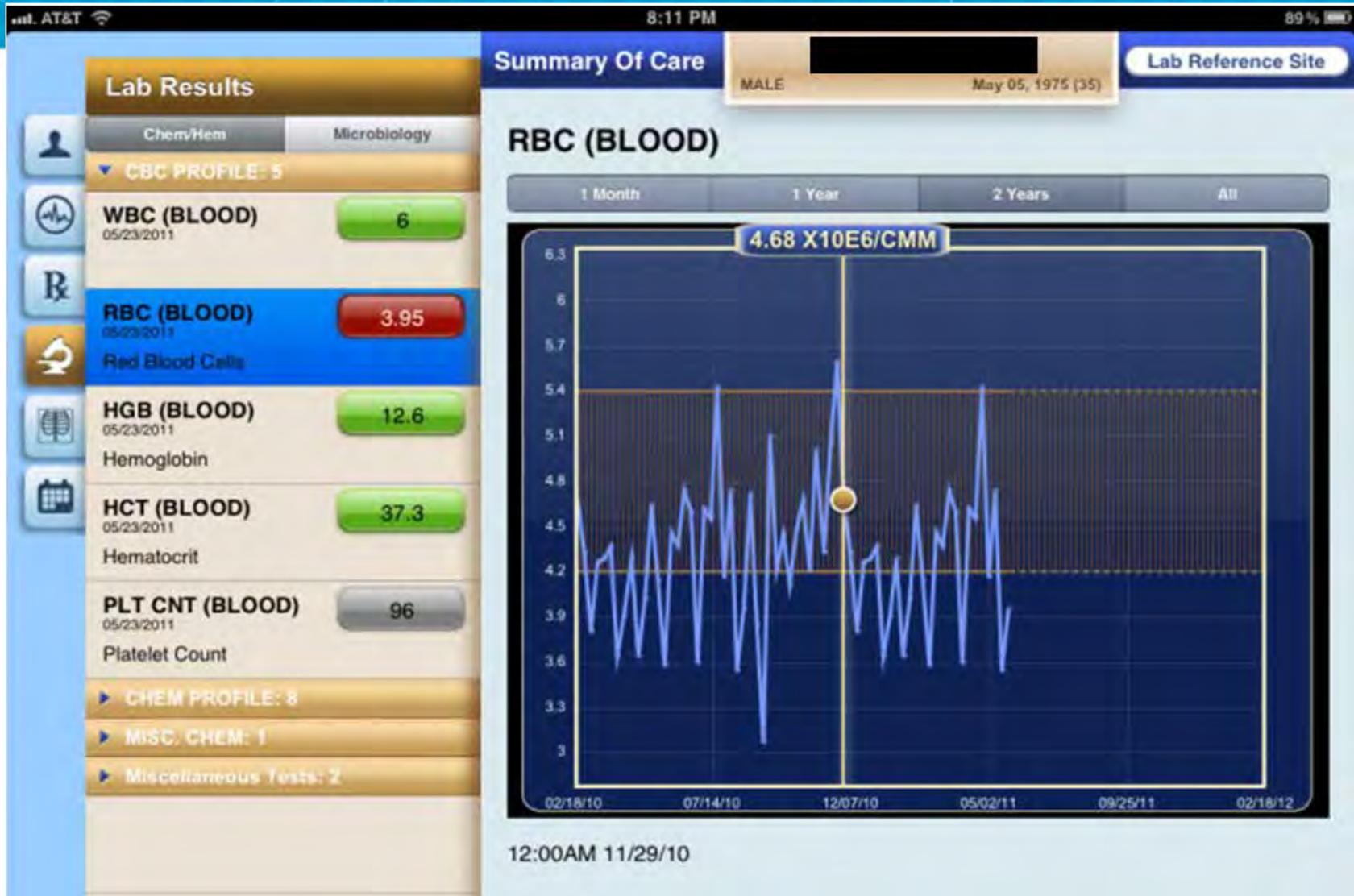
The gold dot represents the average number of minutes (100) a patient spends with a provider per year and the white represents the 525,600 minutes in a year



VA Mobile Strategy Timeline



DC Pilot - Summary of Care App – Lab Results



New Healthcare Team-Facing Mobile Apps

- PatientViewer (expansion)
- Antibiotic Resistance
- Mobile Vista Imaging
- Surgical Pathology/Cytology
- Progress Notes (enter)
- Wound Care
- Immunization Campaign
- Secure Messaging
- Consult Orders Management
- Coumadin Clinic
- Mobile Radiology Imaging
- Radiology Orders Management
- Laboratory Orders Management
- Medication Orders Management
- Patient Consent
- Health Data Reconciliation
- ICU
- Facility and Bed Locator
- Safe Woman Prescribing
- Suite of Nursing Apps

Family Caregiver Pilot Apps

Suite of Apps Pre-loaded on iPads and Distributed to 1,120 Family Caregivers and their post 9/11 Seriously Injured Veterans

- Pain Coach
- Care4Caregiver
- eJournal
- RxRefill
- Summary of Care
- iCal Integration
- Mobile Secure Messaging
- Post-Traumatic Stress Disorder (PTSD) Coach
- Health Advocate
- Notifications

Mobile Health Family Caregiver Pilot Evaluation Study

Primary Quasi-Experimental Study

Longitudinal Cohort Study

Qualitative Study

New Patient-Facing Mobile Apps

- Texting for Health
- Patient Health Inventory
- Caring for Women Veterans
- Preconception/Prenatal
- Maternity Tracking
- Veteran Health Competition
- Biosurveillance Reporting
- Subscription Service for Biometric Monitoring

Example of “How I Feel” – in Personal Health Inventory App Available for Providers to View Data

How I Feel

Move the sliders to show where you are on each scale. You must select a number on each scale in order to save.

Physically, I currently feel...

Miserable (pain, weak, drained) Great (high-energy, strong, fit)

Mentally, I currently feel...

Miserable (anxious, angry, hopeless, alone) Great (happy, hopeful, connected, content)

Day-to-day, to live my life, it is...

Miserable (very hard, exhausting) Great (easy, fulfilling)

Save

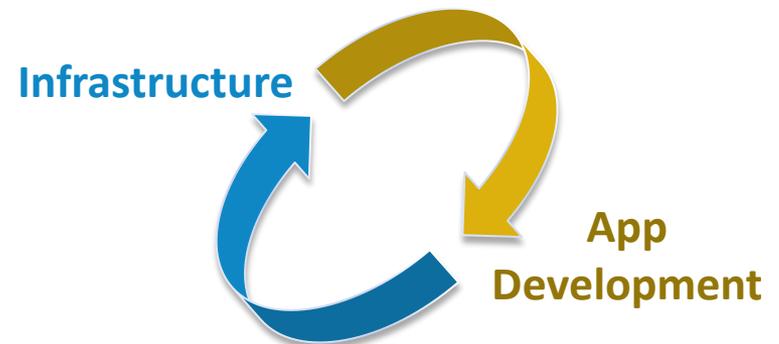
VA Mobile Launchpad



Application Development Foundation



- Security and accreditation
- Pilot infrastructure
- Operationalize
- Enterprise framework



- Application development & distribution
- Application testing & development pipeline
- Ongoing development agility

It's about Security

1

All traffic is single, double, or triply encrypted

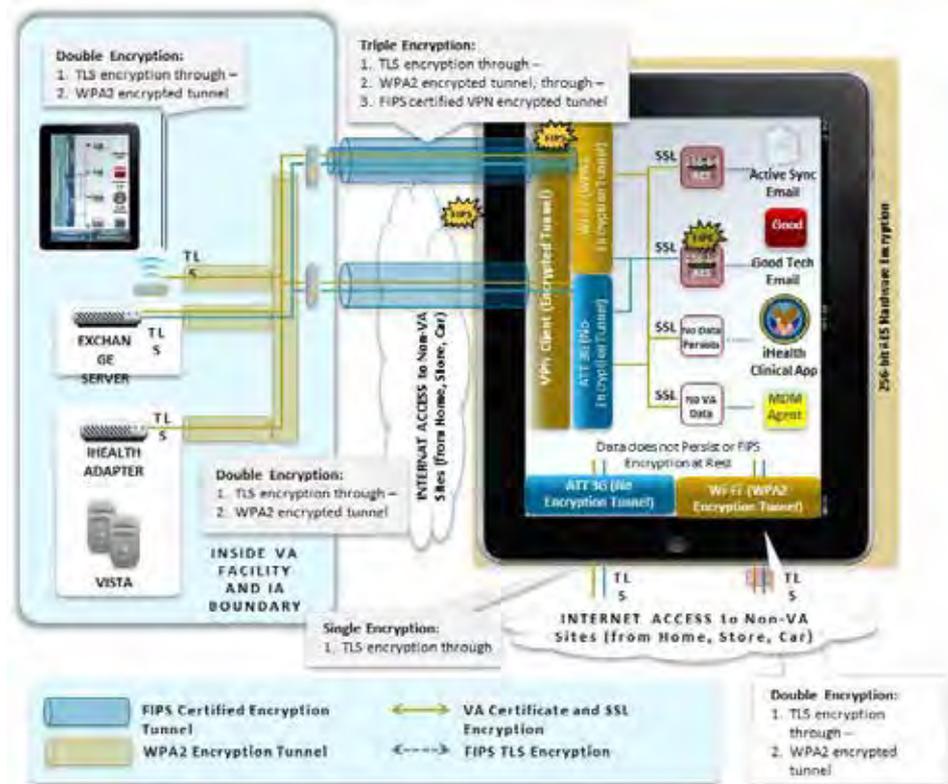
2

Sensitive data does not persist on devices or uses FIPS encryption at rest

3

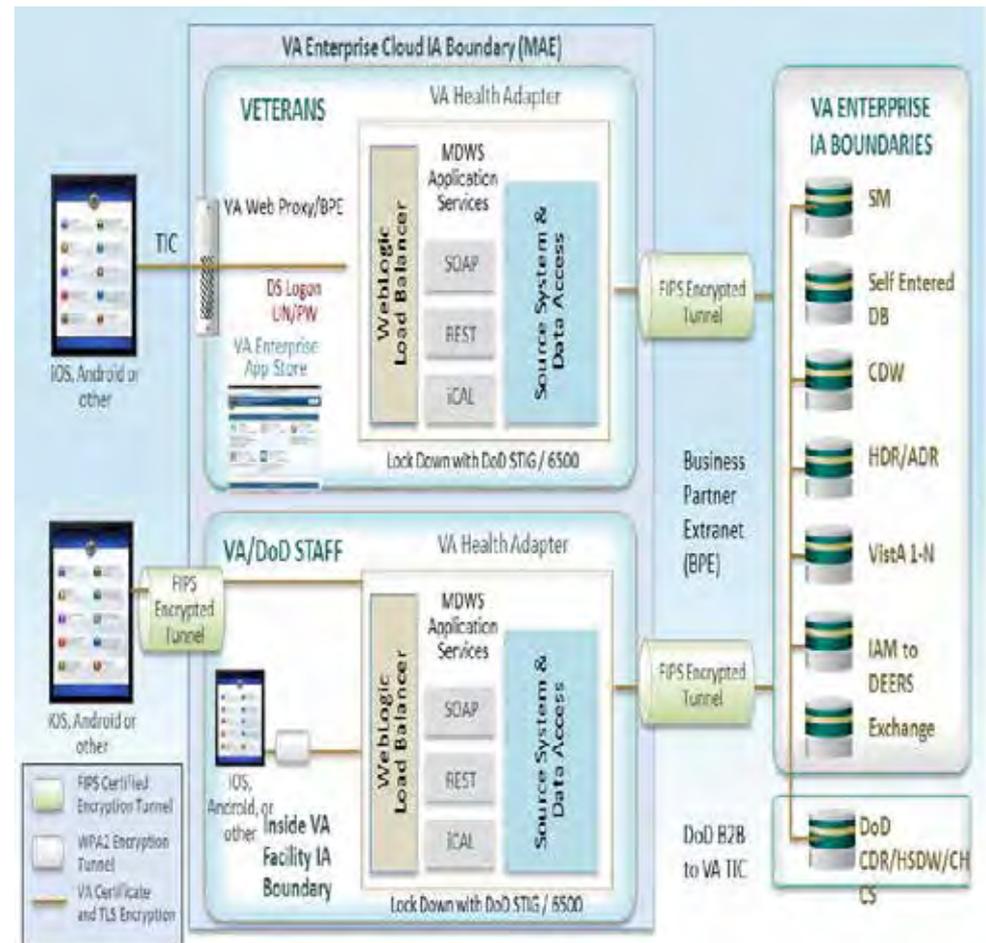
Read only (to start)

VETERANS HEALTH ADMINISTRATION



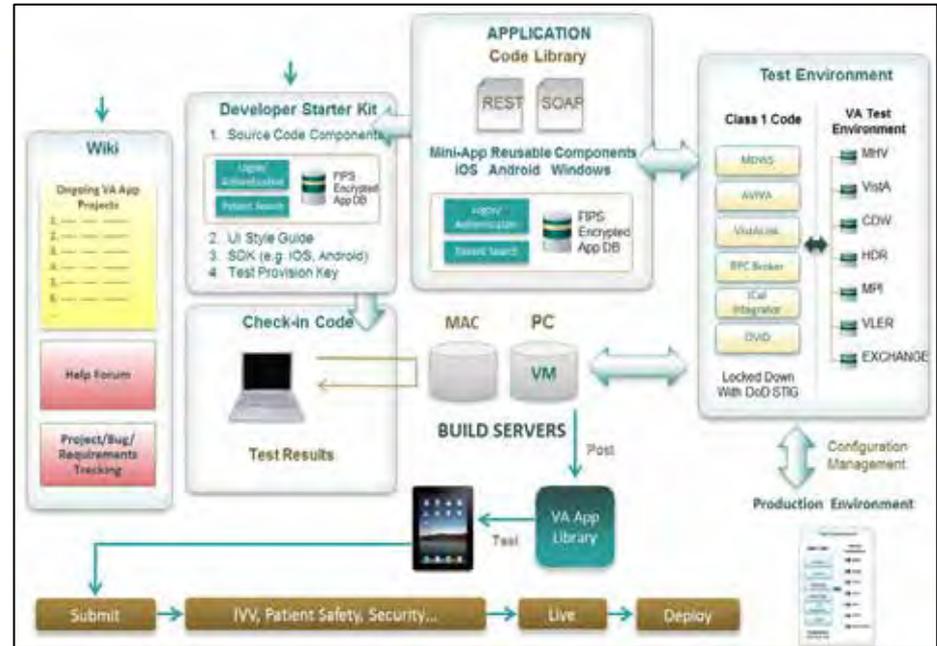
VA Mobile Framework

- **VA Core Cloud Hosted, FISMA High Certified**
- **Data moves through secure encrypted tunnels**
- **TATO**
- **Inside VA's Network**



Mobile Application Environment

- Common Dev Tools
- Common Services/Test Systems
- Dev Knowledge Base
- Project Management Tools
- Production Environment



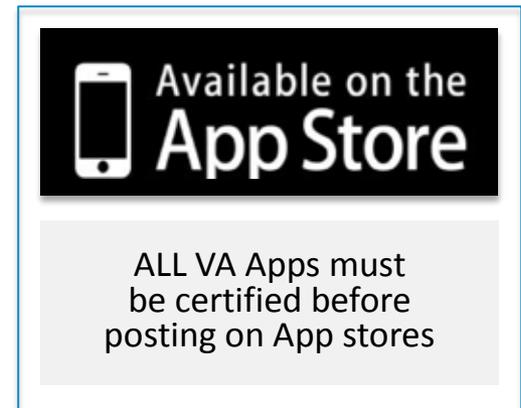
VA's Dedicated Core Cloud Environment



VA Mobile App Certification Process

Reviews for:

- ✓ Business ownership commitment (*Governance*)
- ✓ Aligned with VA business objectives (*Governance*)
- ✓ Sustainment plan (*Governance*)
- ✓ Usability and User Interface Testing
- ✓ VA branding
- ✓ Data and Terminology Standards Compliance
- ✓ Security
- ✓ Privacy
- ✓ System Performance Impact Assessment
- ✓ Patient Safety Assessment & Functional Testing
- ✓ 508 accessibility
- ✓ Clinical review for medical Apps
- ✓ Help screens
- ✓ Software Code Review (Independent Verification & Validation)



RX Refills



Calendar Alerts

Contact Information



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