

# Veterans' Perceptions of Full Access to Their Health Records Through the My HealtheVet Pilot Program

Susan Woods, MD, MPH

Erin Schwartz, PhD

June 20, 2012



**40 Years Ago....**

**.....there was a 'Proposal'**

## SOUNDING BOARD

### GIVING THE PATIENT HIS MEDICAL RECORD: A PROPOSAL TO IMPROVE THE SYSTEM

DISSATISFACTION with the functioning of the medical-care system has become widespread. Physicians and patients find this undesirable.<sup>3</sup> In addition, inadequate transmittal of understandable information from physician to patient largely accounts for the widespread phenomenon of patient noncompliance with professional recommendations.<sup>6,7</sup>

With record in hand, the patient would receive more complete information about his medical encounters, a source of satisfaction and compliance. Patients would accordingly be subjected to fewer repeat tests, would be required to repeat less frequently, and would be able to make more informed decisions about their care. Only three "explicitly or implicitly allow direct access by the patient himself."<sup>1,2</sup> It is indeed paradoxical that records are available primarily for setting the patient and physician against one another, and in most cases, only through the intervention of another professional!

In contrast to this situation, implementing the Proposal would always provide a physician direct access to the history of the patient's previous care, complete with base-line data, drug schedules (a major problem), hypersensitivities, etc. Patients would accordingly be subjected to fewer repeat tests, would be required to repeat less frequently, and would be able to make more informed decisions about their care.

“with record in hand, the patient would...

....get more complete information, a source of satisfaction

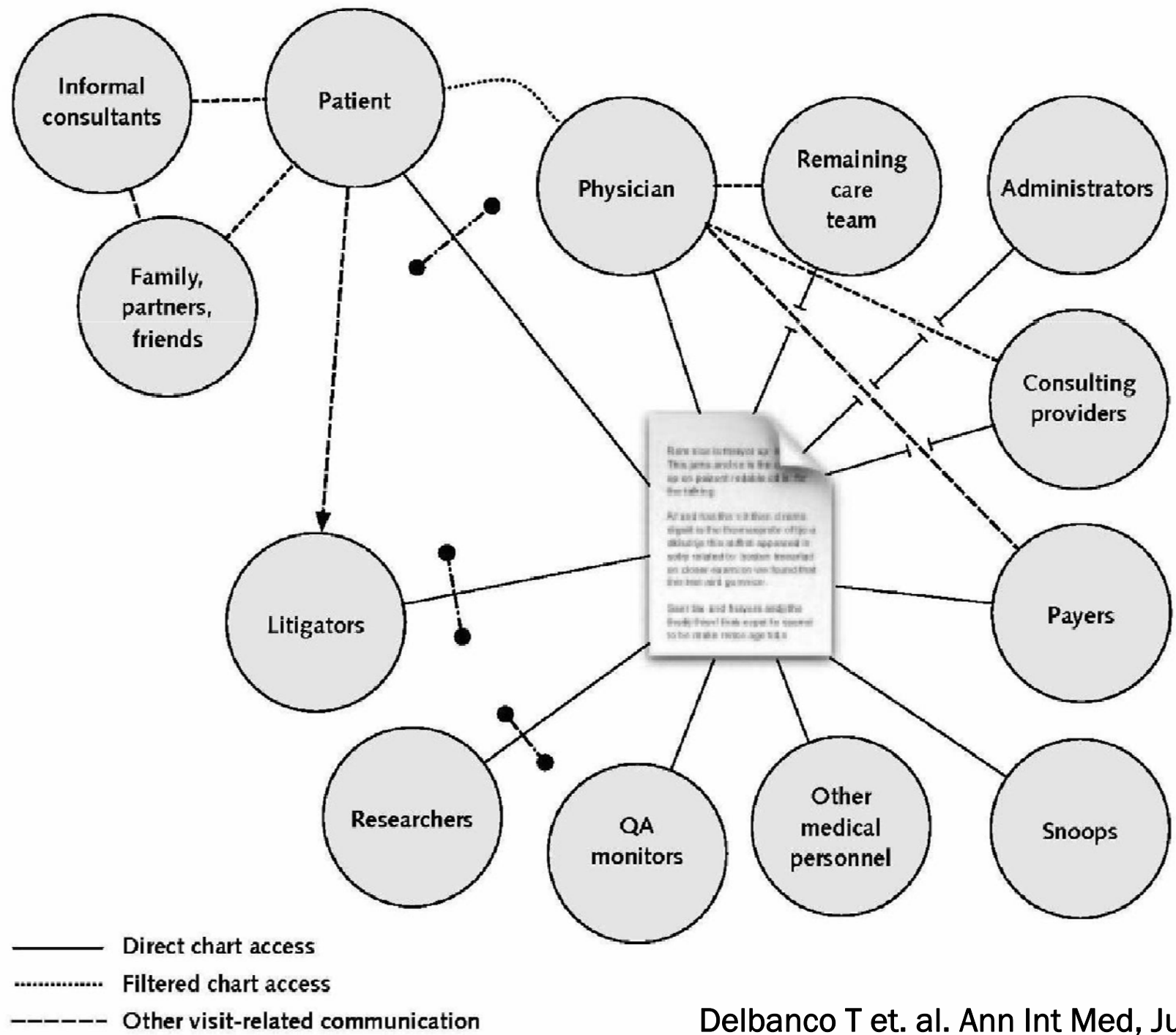
.... have higher compliance by less reliance on memory

....might even result in fewer mistakes”

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In contrast to this situation, implementing the Proposal would always provide a physician direct access to the history of the patient's previous care, complete with base-line data, drug schedules (a major problem), hypersensitivities, etc. Patients would accordingly be subjected to fewer repeat tests, would be required to repeat less frequently, and would be able to make more informed decisions about their care.

Figure. Access to doctors' notes.



# Background

- In 1996, HIPAA established the right of patients to review their medical records or request amendments
- Yet few do, due to lack of awareness or because of an arduous process
- When surveyed, most adults indicate that they want full access to their records

# Background

Clinician concerns for sharing clinical notes:

- Potential for patient harm
- Patient unable to understand information
- Burden on clinical workflow
- Patients critiquing provider performance

# Shared NHS Electronic Records

- Patient Survey N = 231 (3 practices)
- Access - Kiosk or Internet (HealthSpace)
- Results
  - 86% accessed records
  - Poorer health more frequent access
  - Age, ethnicity not associated with frequency
  - 38% found errors (48% did not take action)
  - 76% more involved in care
  - 9% more worried about health
  - 75% felt more confident in GP (3% less confident)

# Open Notes Study



- RWJF Pioneer Portfolio
- Beth Israel Deaconess, Harborview, Geisinger
- 100 providers and 20,000 patients
- Access provider notes through patient portal
- Email notification with new note upload
- 2010 to 2011 (access continues)
- Baseline and follow-up surveys



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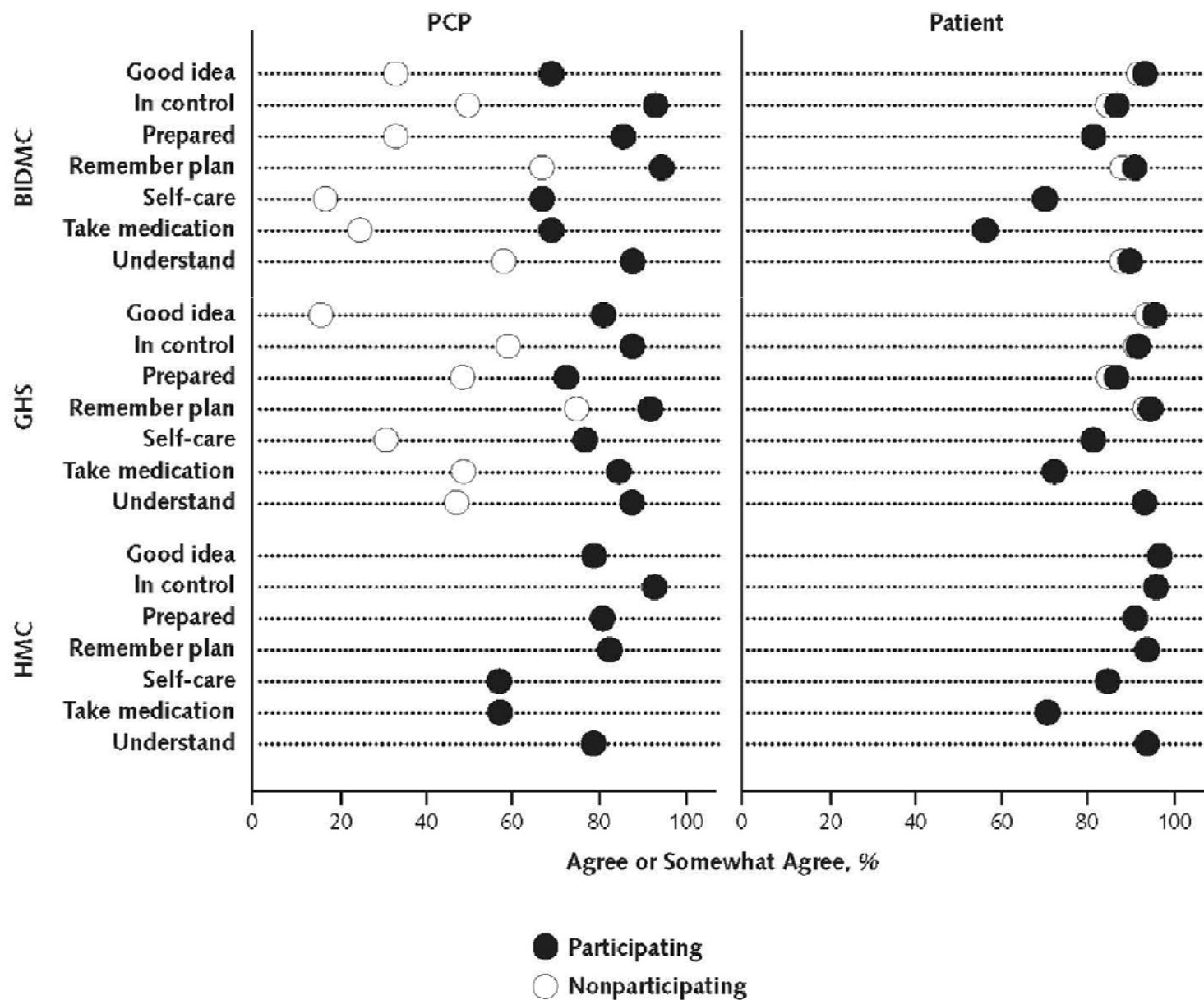
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## News Hub: Giving Patients Access to Doctor Notes 7/20/2010 11:14:06

AM

When patients finish a checkup, doctors record notes on a range of topics. A new study looks

Figure 1. Proportion of PCPs and patients who agreed or somewhat agreed with statements about the potential benefits of open visit notes for patients, by study site.



# My HealthVet Pilot (MHV)

- Initial PHR prototype offered Veteran patients a 'virtual window' into their electronic health record
- The MHV Pilot afforded a unique opportunity to examine patient experience reviewing clinical notes
- Available from 2000 - July 2010
- 9 sites: Oregon, Florida, New York, Washington D.C.
- Total 7,464 enrolled, Portland, OR with 5,361 (71.8%)



X

My Health eVet Pilot Home  
- My Coversheet

**VA Admin Data**

- Demographics
- Appointments
- Wellness Reminders
- Copay

**VA Patient Record**

- Admissions
- Allergies
- Prescriptions
- Problem List
- Progress Notes
- Discharge Summaries
- Vitals
- Lab Chemistry
- Lab Pathology
- Lab Cytology
- Lab Microbiology
- Lab Microscopy
- Radiology
- ECG Reports

**Self-Entered Information**

- Personal Info
- Medical Events
- Medications
- Allergies
- Test Results
- Locations of Treatment
- My Health eLog

**System Options**

- VA Update Request
- VA Update History

# MY HEALTH eVET PILOT

Your Personal Health Journal

HELP

[Health Ed Library](#) | [My Health eVet Pilot](#) | [Feedback](#) | [Search](#) | [Facilities Locator](#) | [FAQs](#) | [Log Off](#)

## VA Update Request (personal health journal of MHV D PATIENT)

Many test results will not be available until 3 - 5 days after the procedure has been completed. These times will vary with the type of tests and procedures. More information about the length of time or what the results mean can be obtained from your clinical care team.

**Request a complete update to your VA Patient Record from all facilities that you are registered with.**

Request all subject areas...

**Request an update for a specific portion of your record and/or from a specific facility.**

Choose which facilities you would like to send requests to. To choose more than one facility hold down the control key and click on your selections with your mouse.

CHY4d

Choose which subject areas you would like to be updated. To choose more than one subject area hold down the control key and click on your selections with your mouse.

# MyHealthVet Pilot

- Access from 2000 until July 2010
- Nine pilot sites: Oregon, Florida, New York, Washington, D.C. enrolled 7,464 Veterans
- Portland, OR had highest recruitment with 5,361 (71.8%) Veterans enrolled

# Purpose

To describe the patients' experience of viewing full medical records including progress notes, through the use of a personal health record (PHR)

# Qualitative Study Design

- Purposeful sampling of only those patients who accessed their records
- Five focus groups conducted between November 2009 and January 2011
- One group comprised of participants who accessed record 1 to 3 times
- The other 4 focus groups were comprised of participants who accessed record 10 or more times

# Methods

- Semi-structured interviews to elicit feedback on:
  - Expectations about MHV Pilot and record access
  - How participants used their health record information
  - Perceptions of access to records, and how it impacted their health and their healthcare
- Themes of interest emerged inductively during analysis after all data are collected
- Two researchers independently coded; team met regularly to reach consensus



# Participants

- Total of 30 Veterans and 6 family members
- Veterans aged 49 to 82 years old
- Four Veterans (11%) were women
- Five of 6 family members were women

# Results - Three themes characterized patient experience

1. Electronic access to all records had an effect on communication during and between visits
2. Patients reported access improved knowledge about their own health, and led to greater self-care & participation in decision-making
3. Electronic access was perceived by patients as improving the quality of their care

# Theme 1: Enhanced communication between patients and providers

- Reminder tool: remembering appointments & scheduling
- Communication tool: valuable supplement to visits & calls
- Health information exchange: coordinating care between VA & non-VA providers
- Preparing for encounters: improved understanding of what questions to ask during a in-person visit

# Quotes: Communication

- “Often I’d get very stressed at a doctor’s appointment, don’t remember half of what’s going on and I could go on to eVet and get my information and go, ‘ok, we’re not in sync with this...that helped a great deal’.”
- “I can go in and ask more intelligent questions and we don’t have to spend as much time with them explaining everything to me. And then, with my stress level up at the doctor’s office, I don’t hear half of it and then we may have to do it again and again and so, it helps us to have better communication”.

## **Theme 2: Enhanced knowledge, self-care, and participation in care**

- Insight into health conditions & provider reasoning: improved understanding of conditions, treatment options, & provider perspectives
- Self-directed research: participants in all groups reported using Internet to look up health-related information
- Personal motivation & behavior change: lifestyle changes were made as a result of reviewing records
- Participatory decision-making: patients used knowledge gained by reading records to make decisions about care

# Quotes: Self-Care & Participation

“Well, you could just pop over to Google or go to the library in there, a dictionary in there, you could pop over to that and check it out and see what it’s saying instead of sitting there sweating it out trying to figure out what it is.”

“Made me feel more responsible for myself too, like there’s no excuses. You know, it’s right there, you know. You can’t use ‘the doctor didn’t tell you’.”

# Theme 3: Patient contribution to care

- Monitoring care: longitudinal views allow patient input on decision-making on care and services
- Advocating for quality care: reminding providers about follow-up or care needed
- Pointing out and discussing discrepancies
- Observations on electronic records: preference for thorough notes; comments on 'templates'

# Quotes: Quality – Patient as Their Own Clinical Reminder

“I had an ultrasound on my liver and they gave the results. I saw it online. It said, ‘Re-do in six months’. Well, six months came around and nothing happened. So, you know, I called the doctor and I say, ‘Well, it said here six months, re-do’ and he said, ‘Well, let me look at your records’. He says, ‘Oh yeah, they did say that’. So, if I hadn’t reminded him, I probably wouldn’t have got it.”



# Quotes: Quality – Patient Decisions

“I don’t think I had to go as often [to the doctor] because...yeah, because I could see my results. I could see what was going on and I didn’t, I didn’t get stressed out waiting to hear back from somebody who might never call me. And so I didn’t, you know, have to go in.”

# Quotes: Quality – Patient as Advocate

“And sometimes, you want to change doctors as a result of what the doctor said. Not because he’s describing it wrong, but he’s describing it incompetently because you know yourself better than he does in many cases.”

# Lack of Significant Harm

No explicit declaration of harm

- Woman (wife of Veteran with cancer) on Operative Note: “I would rather not have known. There was a lot of little things that were wrote, you know, step-by-step what had happened in his operation.”
- “Well, we don’t want to tell the person this because that may make them upset or it may, you know...and I say that’s a lot of bull. I want to know.”

# Conclusion

- Evidence shows that activated patients achieve higher levels of self-care and satisfaction.
- Sharing all clinical notes with patients may serve as an important component of meaningful use of electronic health records and health information exchange.

# Limitations

- Participants from a single medical center, included those using MHV Pilot in time interval
- Responders may represent those more or less satisfied than MHV Pilot users in general
- Many enrolled in Portland had not viewed records 18 months before the study – could have done so previously and had different experience

# Discussion

- Overwhelmingly, patients reported reviewing records was a positive experience and not stressful
- Patients showed greater participation in their health and their healthcare, reviewing data in unpressured manner
- Cumulative effect of access to all health records suggests improved care efficiency and effectiveness while also enhancing the patient experience
- Reports demonstrate change to patient-provider relationship, in a variety of ways
- Clinical workflow impact unclear but suggests it's low

# Implications

As VA moves toward shared access to records

- Traditional roles of patients, providers are challenged
- New skills are needed to enhance communication and leverage opportunities for greater patient participation that will occur with shared records
- Patient access to health records, including clinical notes, may translate into care that is more effective and more satisfying for patients and health professionals

# Study Investigators

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# Questions?



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<http://www.sharedhealthdata.com>

## VISN 22

# ***Veterans Assessment & Improvement Lab (VAIL) Innovation***

PI: Lisa Rubenstein, MD, MSPH

## **Point of Care Enrollment in MyHealthVet:**

***Integrated* Education, Authentication and Registration**

# **POC - MHV iEAR**

**Maher Roman, MD, MBA, FACP**

Chief, Primary Care Teaching Team & Women's Health Center  
Redlands Blvd Outpatient Clinic – VA Loma Linda HCS

**HSR&D CyberSeminars Webinar:**

**"PACT - MyHealthVet: Early Lessons on Enrollment and Engagement"**

**June 20, 2012 12:00 PM - 1:00 PM EST**

# PHR Prior Evidence: Users vs Non-Users

- **Non-VA Studies:** Users more likely to be
  - Female
  - High morbidity
  - Age < 65
  - Primary care provider who uses secure messaging with other patients
- **MHV Study:** Pharmacy, appointments most important to veterans (>85%)
  - 64% want to communicate with their physician

# Aim

- Enhance **teamlet** enrollment of patients in MHV
  - Discuss patient concerns
  - Increase provider awareness
- Assess how often lack of computer access prevents enrollment

## Department of Veteran's Affairs FY12-14 Metrics

- 40% of care non face-to-face.
- 25% of patients authenticated, and 15% opted-in



*Secure Messaging*



HealthVet Volunteer Susan shows Veteran Jerry how to use MyHealthVet -VA Loma Linda Healthcare System  
*Courtesy of Elizabeth Tran, MPh – Health System Specialist Intern)*

Is an Upgraded Account, or IPA,  
for me?

Yes, if you want to:

- View VA Allergies and Adverse Reactions
- Receive Wellness Reminders
- View VA Appointments
- Participate in Secure Messaging
- Be ready to access all new My HealthVet features that will enhance your Personal Health Record

*Ask the My HealthVet  
Coordinator at your  
facility about IPA*

## QI Diagnosis: Mapping the Enrollment Process

- In person authentication (IPA)
  - A release of information
  - Often done by MHV coordinator or somewhere else
- Opting In—at home, on MHV website
  - Name on authentication form often wrong
- Sending a test message
  - No instant reply

# Local Issues Identified

- Drop in voltage from IPA to Secure Message
- Providers (**TEAMLETs!**) are the best **“marketers”** for patients, yet are disconnected from enrollment
  - Little follow-through from brochure to action

# Approach

- Loma Linda VA Redlands Boulevard Quality Council project to promote **Point of Care Enrollment**
- **Rationale:**
  - Teamlets can best overcome patient concerns
  - PACT LVN's have the right skills to assist
  - POC enrollment will simplify and expedite the process



# MHV-POC Toolkit

## **3 Physical Elements (RIB):**

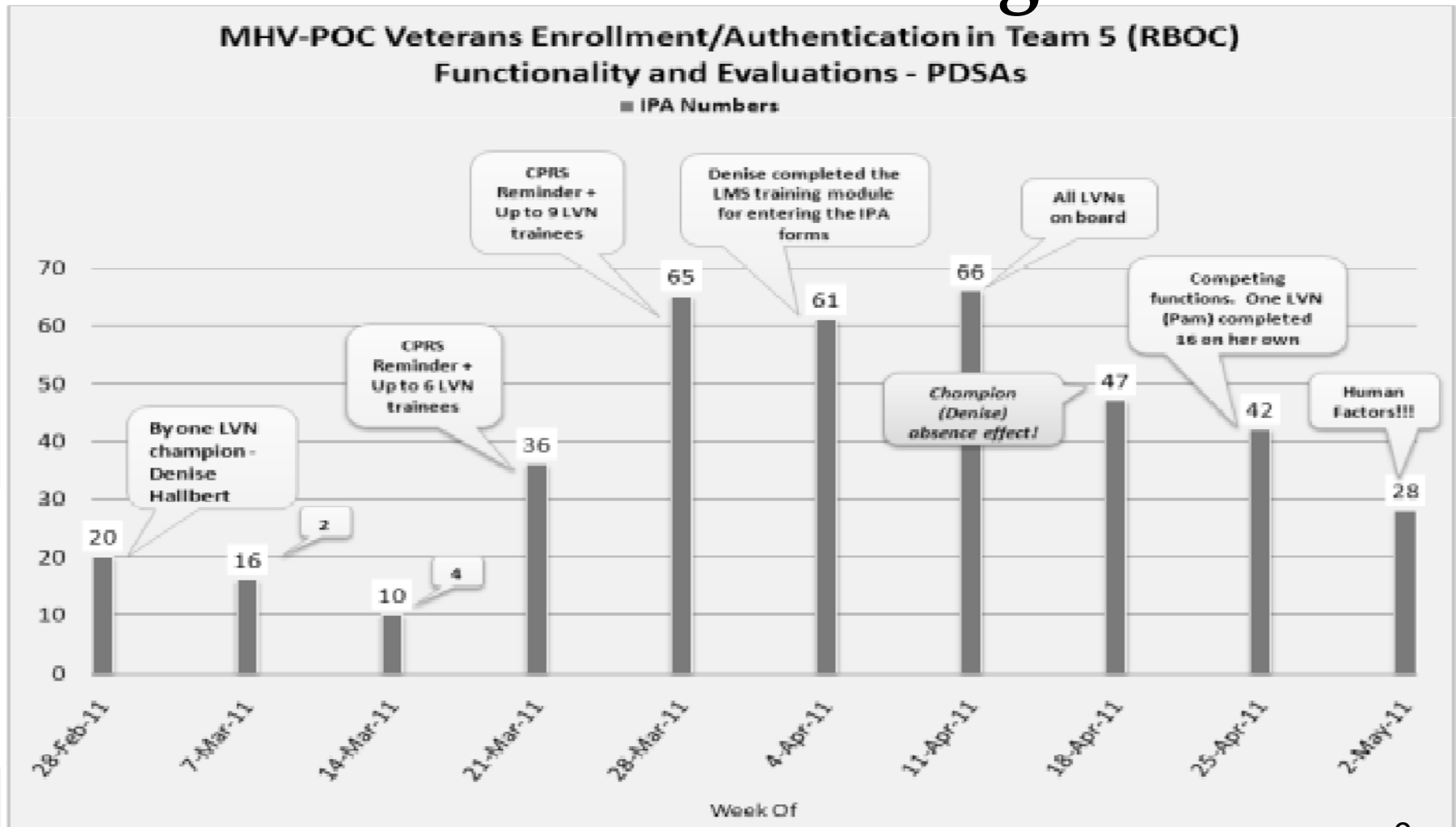
1. Reminder
2. IPA form
3. Brochure

## **3 Functional Elements (EAR):**

1. Education
2. Authentication
3. Registration

# Results of Plan-Do-Study-Act Cycle 1

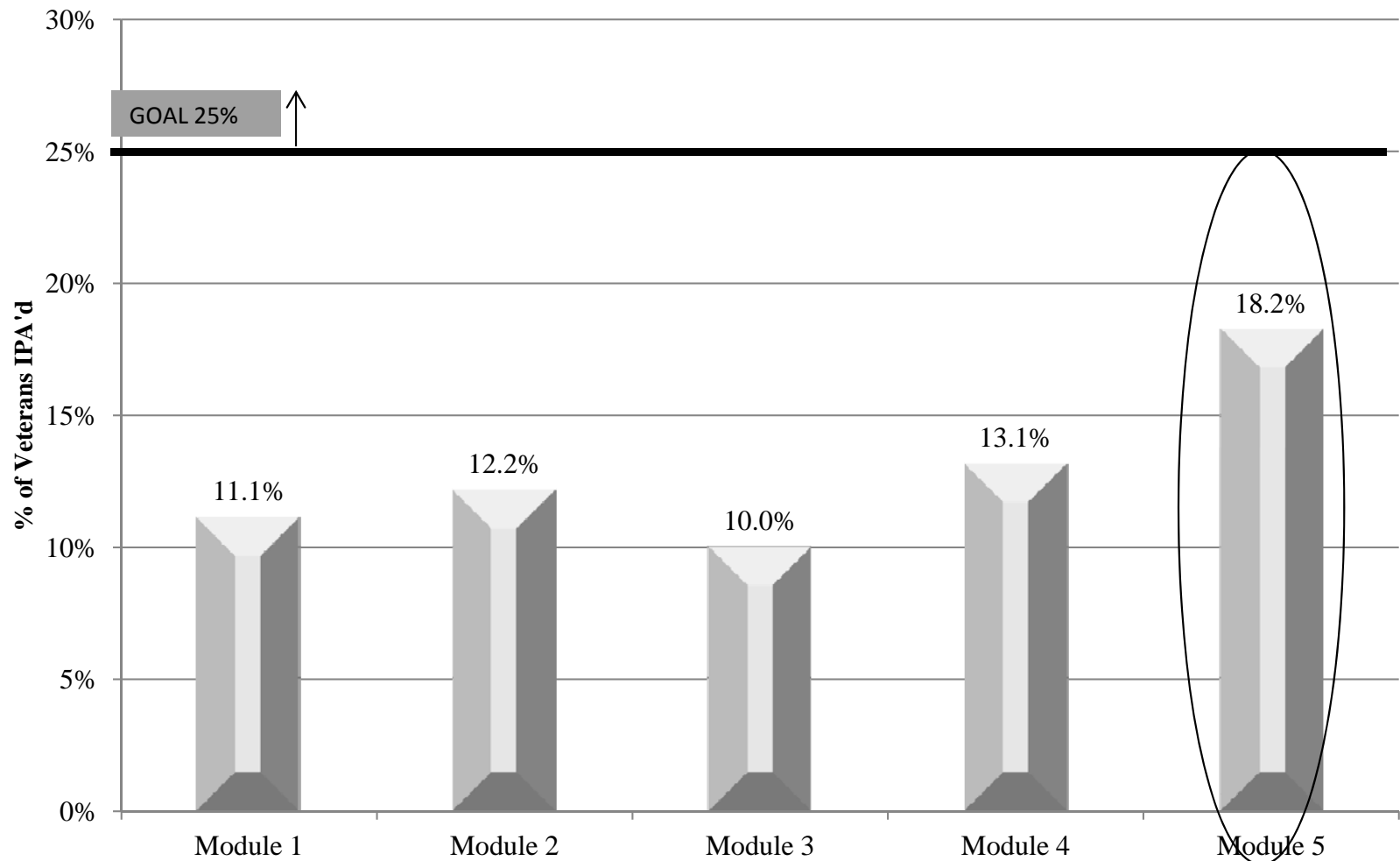
## Success and Challenges!



# Rate of Enrollment and Barriers From Reminder Data

- **1695** patients “*who were never-enrolled in the past*” seen from **March to September 2011**:
  - **742 (44%)** were authenticated on the spot via teamlets
  - **492 (29%)** had no computer/internet access
  - **221 (13%)** were not interested
  - **231 (14%)** other

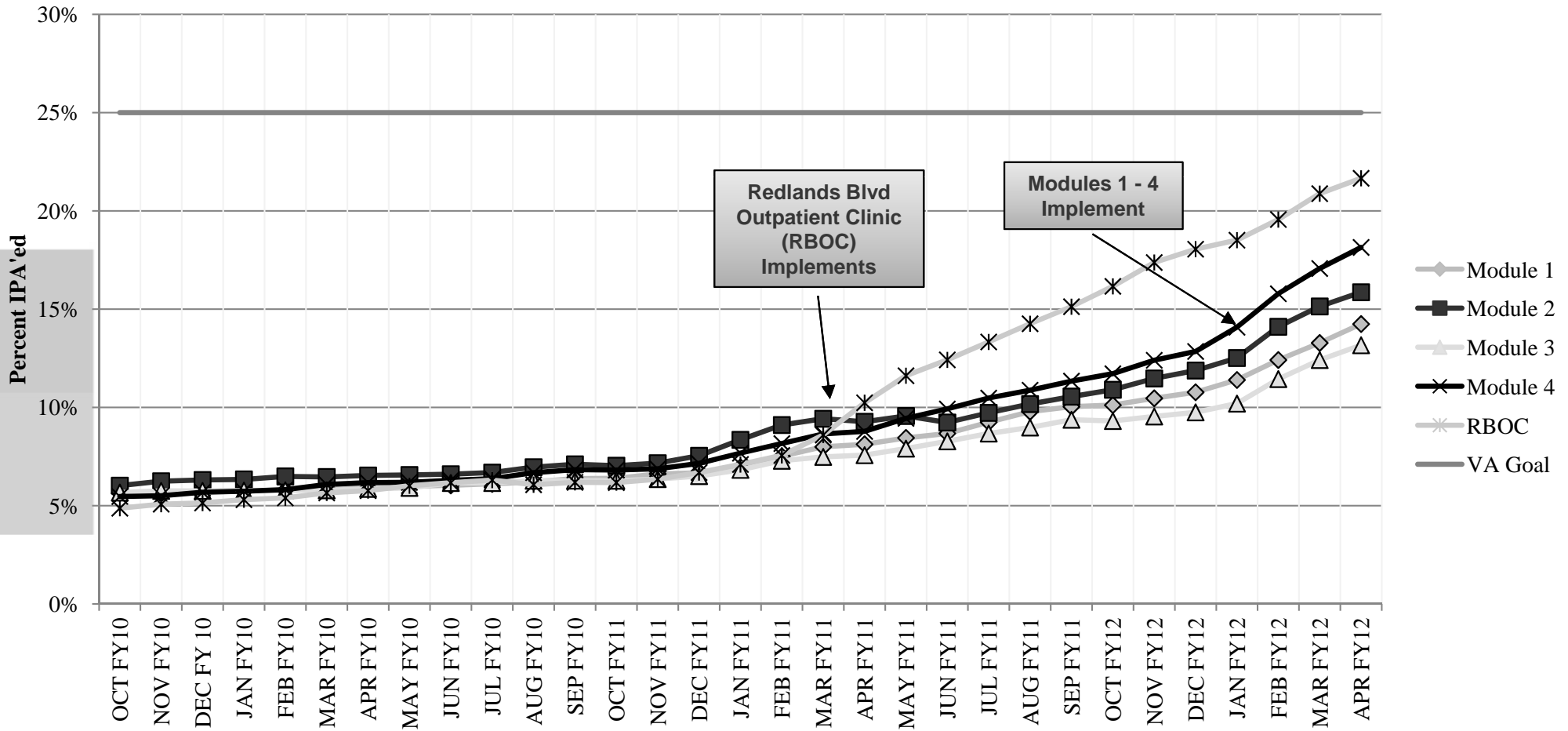
### VA Loma Linda Healthcare System Percentage of Veterans IPA'd for My HealthVet by Module as of January 27, 2012



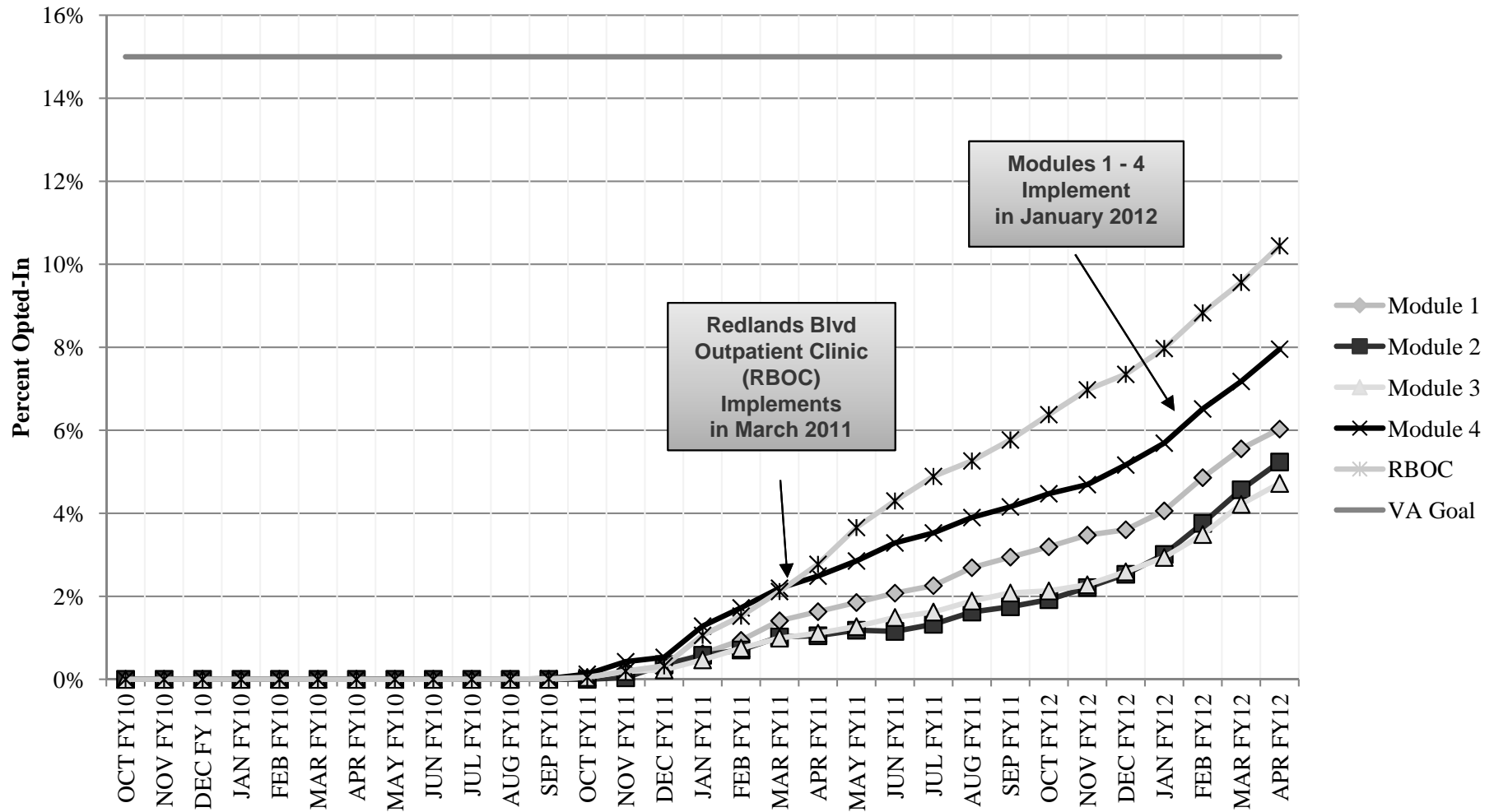
# MHV-POC Spread Progress

- **PDSA cycle #2 (fall 2011) spread**
  - Greater Los Angeles (GLA) at Sepulveda/Dr. Rubenstein's Teamlet (Green Team)
- **PDSA cycle #3 (2012) reminder spread**
  - All Loma Linda (Jan. 2012)
  - All GLA sites VA (Jan. 2012)
  - San Diego VA Oceanside CBOC (June 2012)
  - Long Beach VA (requested May 2012 – implementation pending)

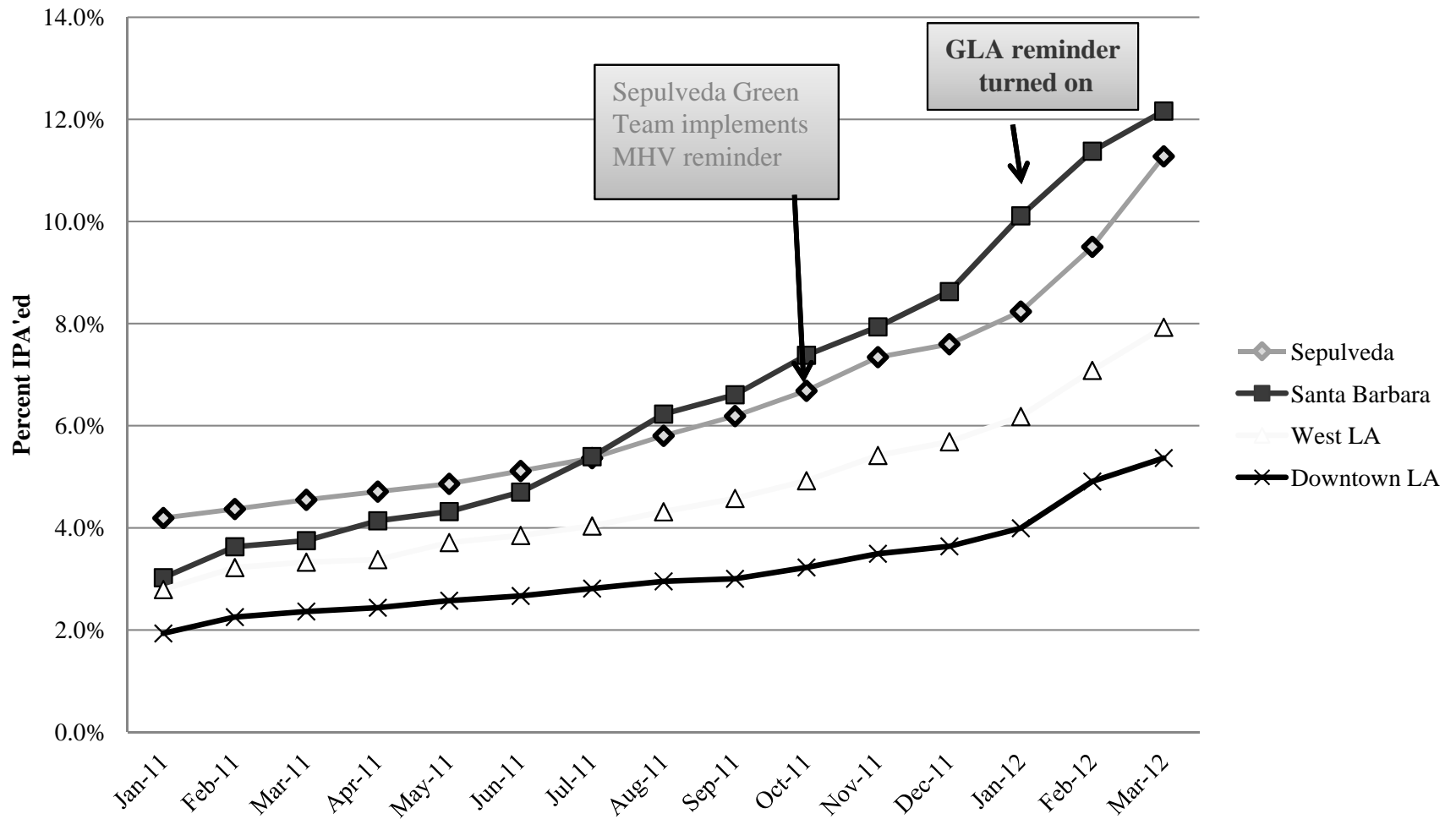
## MHV In-person Authentication – Loma Linda



## MHV Opted-In Loma Linda



## MHV In-person Authentication Greater LA





# MHV-POC Spread Progress Evolution/Adaptation

## What really works?!

- Is it the point of care aspect? *In addition to other enrollment locations!*
- Is it the teamlet? The LVN role is beyond enrollment – “*Secure Message Navigator*” “SMN” is an attractive functionality that seems to work well – what is it?
- Is it that the reminder and what it triggers: Education → Authentication → Registration? *Is the reminder just a catalyst?!*
- Is it the brochure?
- Is it MHV itself – what the veteran and us can do with it or through it?
- Or all of the above? – we’re trying to identify what works – stay tuned!
- Each of the spread sites seems to adapt / evolve the process – we’re learning from them – VAIL is after all a “LAB”

# What is in it (MHV) for me ( theTeamlet)?

*Teamlet = Patient, Nurse, Physician (PNP)*

- **Asynchronous communication and care**
- **Improved VIRTUAL Access**
- **Improved Coordination**
- **Reduction in Walk-ins**
- **Reduction in phone calls**
- **To be tested – improved clinical outcomes!**
- **Well MHV (and secure messaging) is in line with PACT pillars: Access, Coordination, Practice Redesign**

# Where to go from here?

- Are we there yet!
- Well – what is “there!”
- ***It is just the beginning!***

# Thank You

Loma Linda **VAIL** Leading Implementation  
and Functionality Evaluation

**(VAIL-LIFE)** Team:

Essence Carmichael, MBA, Loma Linda

George Isaac, MD, Loma Linda

Adewale Ajumobi, MD, MBA, Loma Linda

Susan Stockdale, PhD, Director, VAIL-PCC

Maher Roman, MD, MBA, Loma Linda (Lead)

MY HEALTHEVET COORDINATORS

Sharon Hartman, Loma Linda

(Developed Veteran-Friendly MHV Brochure)

Kevin Ligon, Sepulveda

VA LOMA LINDA NURSING SERVICE

Especially:

Denise Hallbert, LVN, Loma Linda

Pamela McCarty, LVN, Loma Linda

VAIL Electronic Measures Workgroup  
(Especially Susan Vivell, PhD, MBA)

VAIL-PCC Staff, Quality Councils and  
Steering Committee

VAIL Loma Linda Quality Council

John Byrne, DO, Loma Linda  
(Programmed Loma Linda Version of the Reminder)

Caroline Goldzweig, MD, VA GLA  
(Programmed the Sepulveda Version of the Reminder)

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6/20/2012	MyHealthVet: Early Lessons on Enrollment and Engagement	Patient Aligned Care Teams (PACT) Demonstration Labs	Roman, Maher Schwartz, Erin Woods, Susan Lisa Rubenstein
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If patients are able to see everything in the records, how does that affect court issues? Are providers and healthcare team members are to monitor what is being written in the records?

SW: Patients have a legal right to see their medical record, it is a national law. All individuals who document in the record should understand that is an option for Veterans. Now, this is only available on paper and requires the patient to go to the Release of Information Office and submit a written request. The MyHealthVet Pilot offered the records electronically. This project is over; however, VA is moving ahead to offer this broadly, at some point in time in the future.

The speaker needs to be aware that there were 552,662 unique women Veterans enrolled in the VHA in FY11. Your “rapid” research review IS helpful in identifying the potential benefit of MyHealthVet Enrollment to OUR women Veteran Health Care Program.

LR: Thanks for the comment; will remember to continue mentioning the role of MHV for women and the need to explore tailoring to this group.

Do you have any preliminary data on how the clinical reminder or utilizing LVN has worked for enrollment?

LR: QI results strongly support the important role of the LVN in this process. That being said, LVN’s have a variety of key roles on teamlets, and spread sites (after the initial pilot site) have all added additional personnel to the enrollment team, including e.g., trained veteran volunteers, clerical support staff who roam through the waiting rooms and talk to veterans about MHV, manned kiosks in the waiting room, and probably others. These ideas are still being tested out, and we will see which ones turn out to be most productive and feasible. However, it is our strong sense so far that having the LVN educated about MHV and how to enroll is pivotal to success, even if other personnel help complete the enrollment process, because of the link to the primary care provider, the reminder, and the clinical visit itself.

Concerning the secure messaging, which medical staff are pts able to communicate with? For example if a patient has a nurse care manager, can they communicate with them as well or is it limited to MDs/PA-C/NP?

LR: Definitely, the nurse care manager can answer and is encouraged to do so. MHV is designed such that all teamlet members can be identified as part of the answering team, and the responsibility for monitoring messages can also be designated. On my teamlet, my LVN monitors the messages that also come to me, and answers or designates responsibility (assigns) to someone else on the team or teamlet. When I complete a message, I “assign” the message to myself to complete it.

Is there any timeline on the mobile app efforts? Will it be one big app or separate apps for the different modules of MHV?

SW: The current mobile effort is limited to piloting of a “Clinic-in-Hand” project, offering family caregivers for OEF/OIF Veterans with illness or disability. The plan is to ultimately have a “VA app store”. The goal is for veteran users to have a consistent experience – desktop or mobile – of VA functions, including those currently available in MyHealthVet.

6/20/2012	MyHealtheVet: Early Lessons on Enrollment and Engagement	Patient Aligned Care Teams (PACT) Demonstration Labs	Roman, Maher Schwartz, Erin Woods, Susan Lisa Rubenstein
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Please give specific advantages and disadvantages - rural patients

LR: The system has enormous potential applicability to rural patients. As a clinician, for example, I have patients who live at a distance whom I ask to update me monthly on their status. I can tell them what to monitor. I can also work with my nurse care manager on this. That way, the patient can have fewer in-person encounters but still be closely monitored if need be.

Does a doctor's communication with a Veteran via MyHealtheVet count as a "visit" according to Medicare guidelines? (Home health agencies can't provide care under Medicare payment without a recent doctor visit.)

LR: There is a way to count the MHV communication as a visit, but it involves copying into an encounter code note so it is an extra step. Pasting the MHV communication stream into the record from MHV is very easy, but does not create an encounter.

Thank you Dr Rubenstein for this excellent presentation. --- How long does it take to train and get a site started in a similar process? -- Mo (Maurilio Garcia-Maldonado, MD)

LR: Hi, Maurilio! Your question couldn't have been better timed as we are just completing a tool, or bundle, for the purpose of helping sites. If you would agree to let us know how it works and give us comments on how to improve it, we'd be happy to send it to you.

For the pilot study- I know your sample was over 40; any thoughts about how younger vets might respond?

SW: That is a good question, but we can only theorize that many of the participants' views and experience will be similar in a younger population. We know that younger Veterans are more likely to be using technology, and have less desire to come see us in person...so we suspect there will be positive value of enhancing MHV functionality for younger Veterans and their caregivers and family members.