

A randomized study of the personal health record in the public health setting

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Outline

Main Points

Background

Provide a brief glimpse of the system

What is the data telling us?

What worked and what did not work

Future activities

Main Points

The study design is acceptable

Patients will enroll in a RCT

Investigators remain blinded to the data

Patients have some challenges such as maintaining their online identity

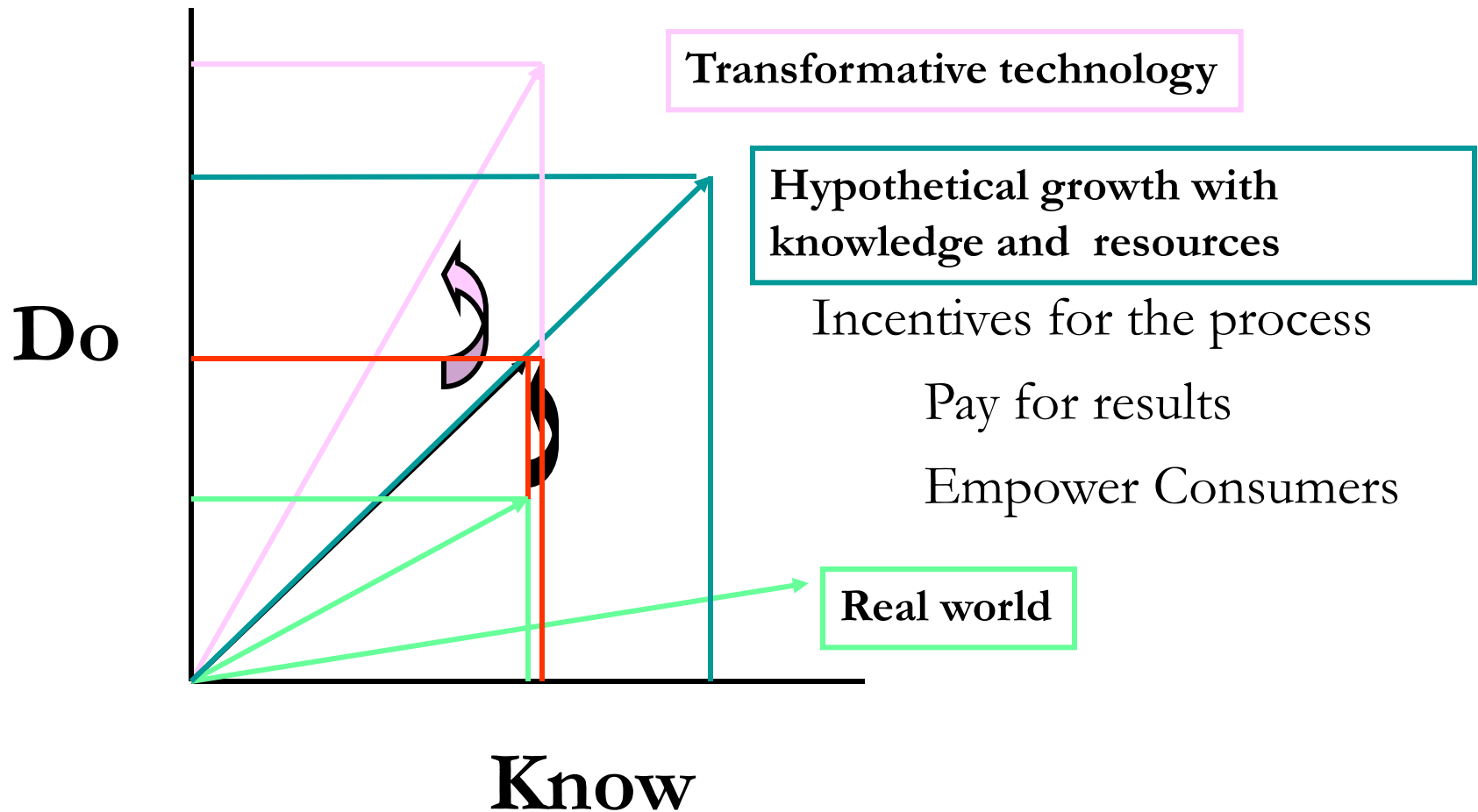
How to reconcile research data and clinical care remains an issue

We will unlikely reach our target full enrollment

Background

- PHRs are becoming more common
- PHR functionality is a criteria for EMR certification under Meaningful Use criteria
- PHR use by persons in public health settings is desired by patients and clinicians
 - Information exchange (lab data)
 - Scheduling appointments
 - Reminders (appointments, medications)
 - Communication (immunizations, concerns)

Do vs. know



Goal of the project

Our central hypothesis is that a secure PHR that combines meaningful information, web-based tools for support and reminders for patients will provide a substantial opportunity to promote self-management and will lead to improved health outcomes

To test our hypothesis we are performing a randomized controlled study to evaluate the biologic outcomes between persons randomly assigned to full use PHR compared with persons assigned to deferred access.

The future is already here, it's just not
evenly distributed

William Gibson

The Economist 2003



About the Study

- 600 patients followed for one year
- Half are randomized to full access of their online PHR and half randomized to receive ONLY surveys in the PHR without health information
- Patients are incentivized by receiving Starbucks gift cards as well as entries into a monthly groceries drawing worth \$60
- Enrollment period from 6/24/09 to 6/1/10

myHERO - My Home - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Refresh Mail Print Internet Options Help

Address <https://myhero.sfdph.org/myhero/svc/DanaInfo=.asgiktmv8H1yxL7q7vQwwC,SSL+default.aspx> Go Links

myHERO English

My Home My Account My Health Record My Surveys My Visits Clinic Info Help Links Welcome myhero86 [Logout](#)

My Home

[My Account](#)
Update your contact information

[My Health Record](#)
View your meds, labs or conditions
Renew your prescriptions
Record your blood pressure, weight or glucose

[My Visits](#)
Request appointments

[Surveys](#)
Complete surveys regarding your health and experiences with your Provider

Welcome!

Dear myHERO user:

Welcome to myHERO and the AHRQ study. We want to thank you again for agreeing to participate in this exciting study! Now that you have successfully registered, you will be able to see your health information as well as a section where you will complete all of your surveys for the research study.

Over the next year, you will see 3 groups of surveys available in the **My Surveys** tab. The first group of 9 surveys is available now, another group will be available in 6 months and a final group in 12 months. We'll send you an email when the 6 and 12 month surveys are ready for you to take. For completing each group of surveys, you will get a \$5.00 gift card to a local restaurant and for completing each individual survey, you will be entered into a monthly grocery drawing worth \$65.00. Each survey will have an expiration date, shown in the survey list. You may save a survey you are working on and return later to finish it, but you must complete it before the expiration date.

The myHERO web page has many tools that we hope you find helpful. Under the tab that says **My Health Record**, you can see your allergies, blood pressure (that you record), conditions, glucose levels (that you record), lab results, medications, weight (that you record) and notes. This information is updated any time your provider changes your medical record. It is important to know that there will be a two week delay of your Lab results. For the **Meds** section, you will see a list of your current meds and med pictures if available. You can find more information about a medication by clicking on the medication name. Under **Conditions**, you will find your current diagnoses with links to more information (if available)

Done

Start 4 Internet Explor... EndNote 9 - Patient ... My Computer Inbox - Microsoft Ou... Deadline for Reviews... Menu.PDF - Adobe A...

Internet 7:54 AM

My Home

[My Account](#)

Update your contact information

[Surveys](#)

Complete surveys regarding your health and experiences with your Provider

Welcome!

Dear myHERO user:

Welcome to myHERO and the AHRQ study. We want to thank you again for agreeing to participate in this exciting study! We hope that you will find the myHERO surveys to be very useful! Now that you have successfully registered, you will have two months to complete the first group of your surveys.

Over the next year, you will see 3 groups of surveys available in the My Surveys tab. The first group of 9 surveys are available now, another group will be available in 6 months and a final group in 12 months. We'll send you an email when the 6 and 12 month surveys are ready for you to take. For completing each group of surveys, you will get a \$5.00 gift card to a local restaurant and for completing each individual survey, you will be entered into a monthly grocery drawing worth \$65.00. Each survey will have an expiration date, shown in the survey list. You may save a survey you are working on and return later to finish it, but you must complete it before the expiration date.

Thank you for your interest in this study, we hope you will have a positive experience with myHERO. If you have any problems with the myHERO site, you can email us at myherosupport@php.ucsf.edu.

[Take a Survey now!](#)



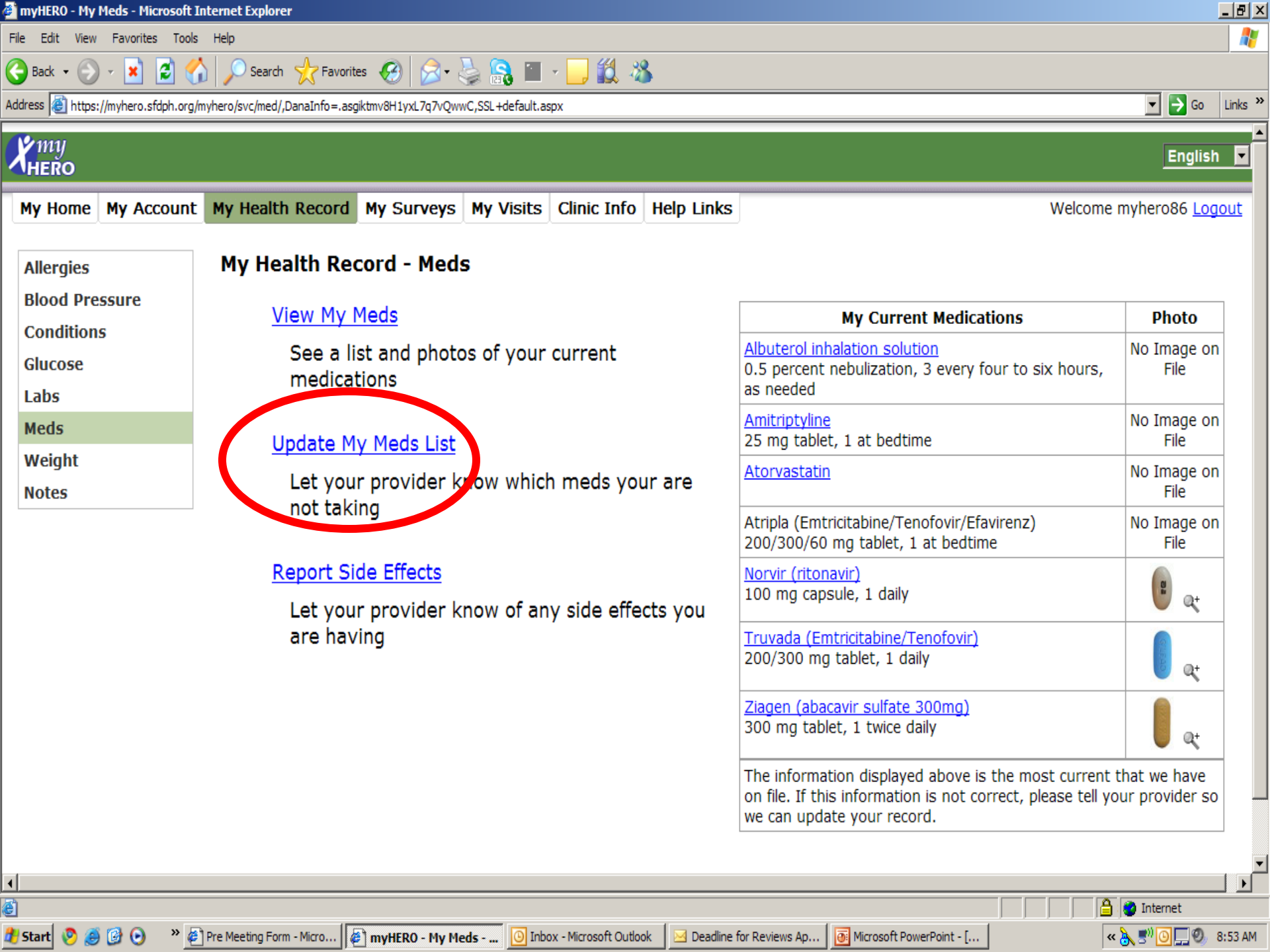
My Surveys

Survey Name	Status	Expires
Internet and Health	New!	
Well Being	New!	
How I Feel	New!	
The Mood Screener	New!	
Medications Survey	New!	
Smoking	New!	
About My Provider	New!	
About Me	50% Complete	
My Annual Health Survey	92% Complete	4/07/2011
Satisfaction with MyHERO	New!	

Thank you for completing these surveys. You are participating in a one of a kind study! All of your answers are private and will not affect your care at Ward 86. Please answer the questions the best you can. You may skip questions you do not want to answer.

You can always stop a survey in the middle and finish it later. Once you have finished a survey, it will disappear from your surveys list.

[myHERO Study Consent Document](#) 



English

[My Home](#) [My Account](#) [My Health Record](#) [My Surveys](#) [My Visits](#) [Clinic Info](#) [Help Links](#)Welcome myhero86 [Logout](#)[Allergies](#)
[Blood Pressure](#)
[Conditions](#)
[Glucose](#)
[Labs](#)
[Meds](#)
[Weight](#)
[Notes](#)

My Health Record - Meds

[View My Meds](#)




See a list and photos of your current medications

[Update My Meds List](#)

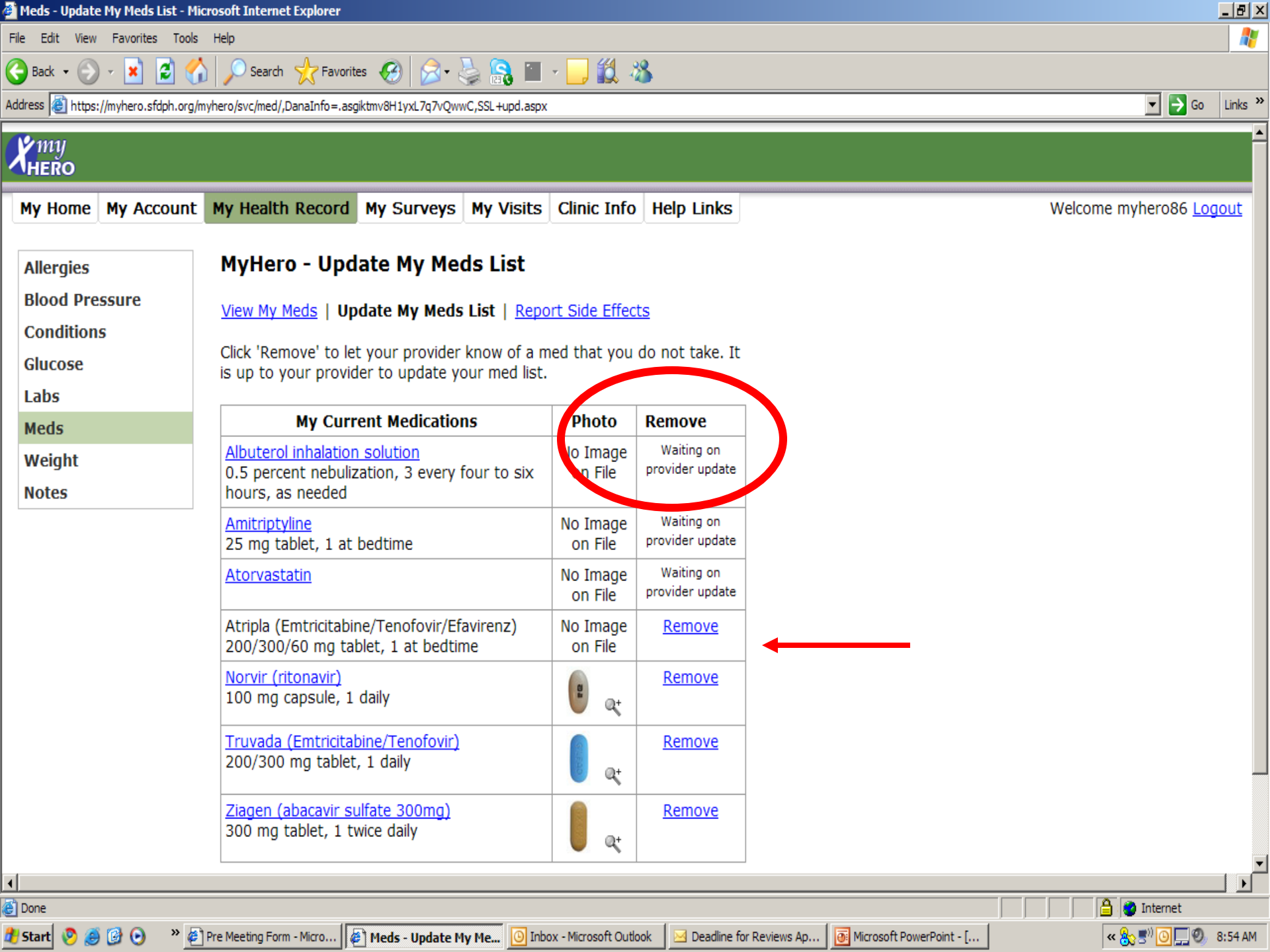
Let your provider know which meds your are not taking




[Report Side Effects](#)

Let your provider know of any side effects you are having

My Current Medications	Photo
Albuterol inhalation solution 0.5 percent nebulization, 3 every four to six hours, as needed	No Image on File
Amitriptyline 25 mg tablet, 1 at bedtime	No Image on File
Atorvastatin	No Image on File
Atripla (Emtricitabine/Tenofovir/Efavirenz) 200/300/60 mg tablet, 1 at bedtime	No Image on File
Norvir (ritonavir) 100 mg capsule, 1 daily	
Truvada (Emtricitabine/Tenofovir) 200/300 mg tablet, 1 daily	
Ziagen (abacavir sulfate 300mg) 300 mg tablet, 1 twice daily	

The information displayed above is the most current that we have on file. If this information is not correct, please tell your provider so we can update your record.



My Current Medications			Photo	Remove
Albuterol inhalation solution 0.5 percent nebulization, 3 every four to six hours, as needed	No Image on File	Waiting on provider update		
Amitriptyline 25 mg tablet, 1 at bedtime	No Image on File	Waiting on provider update		
Atorvastatin	No Image on File	Waiting on provider update		
Atripla (Emtricitabine/Tenofovir/Efavirenz) 200/300/60 mg tablet, 1 at bedtime	No Image on File	Remove		
Norvir (ritonavir) 100 mg capsule, 1 daily		Remove		
Truvada (Emtricitabine/Tenofovir) 200/300 mg tablet, 1 daily		Remove		
Ziagen (abacavir sulfate 300mg) 300 mg tablet, 1 twice daily		Remove		

[Back to Survey List](#)

My Survey - Medication

This is your medication list from your doctor. Please answer YES if you take the med (or sometimes take the med) and NO if you don't.

My Current Medications	Photo	Do you take this Med?
Atenolol 25 mg tablet, 1 daily	No Image on File	<input type="radio"/> Yes <input type="radio"/> No

Do you take any other medications? If yes, please list: (example: medication x, medication y, ...)

[Done. Submit Survey](#)

Provider Role

- For each patient that have agreed to take part in the study, the clinician is asked to complete a single survey at baseline, 6 months, and 12 months (based on when the patient first registered)
- Clinicians have 4 months to complete the survey
- Study team sends weekly emails with the names of newly registered patients

Study participants-patients and clinicians

336 Patients have consented for the study

- 2 deceased patients
- 8 withdrawn (reasons recorded)

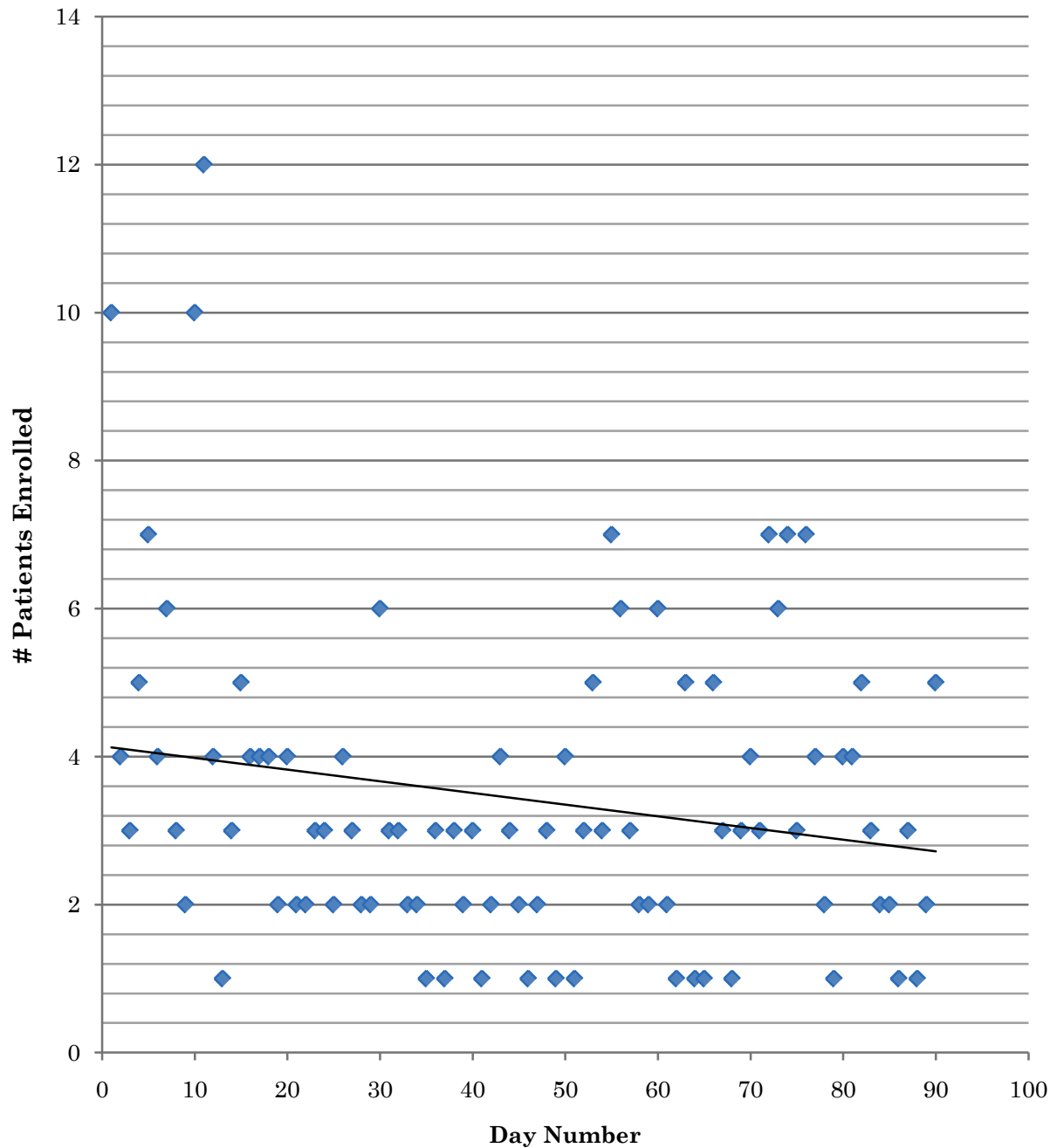
59% of patients have taken one or more baseline surveys (N=254)

61% completion of baseline (N=199)

45% completion of R2 surveys (N=38)

149 Provider surveys completed 46% PCPs have taken 1 or more surveys (N=18)

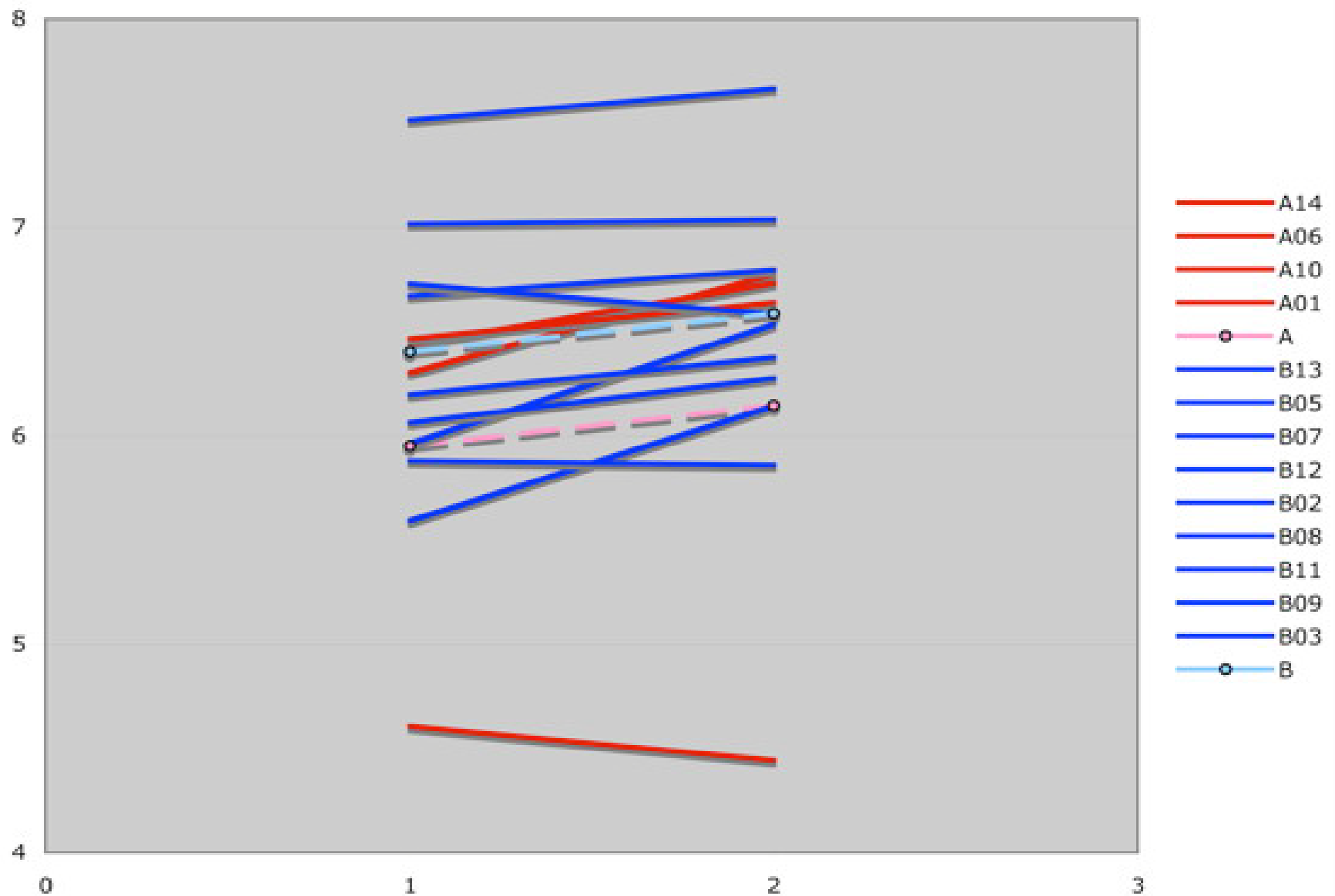
AHRQ Enrollment Numbers (Day)



◆ Number of Patients Enrolled (by day)
— Linear (Number of Patients Enrolled (by day))

$$y = -0.0158x + 4.1398$$

CD4 levels on log scale, by Collection time
(dark colors are patients' levels; pale colors are Arm means)



How do we perform follow-up?

Email sent every other week

Phone call* every week

- Cannot leave messages
- Set up “appointments” for patients to get back into their email/myHERO account:
 - Many have forgotten their username and/or email account information
 - 11 email changes (create new email address in the database)

*Major issue: phone numbers are inaccurate

Recent changes to improve follow-up

CHR approved advertising video for patient waiting room

Can give PHR username over the phone

Observing a better survey completion rate
(even though it is taking a longer time) in the clinic!

Observations from Recruitment

- Patients who are “full” users are very excited about seeing their personal health information.
 - “This is the coolest thing I have ever seen”
 - “This is truly amazing”
- Deferred users are not thrilled with their assignment but there is no differential drop-out rates

Computer Skills

- 3 types of users:
 - Computers are completely foreign
 - Somewhat familiar with a computer
 - Completely comfortable with a computer
- ❖ Challenges: We can only teach so much in one sitting
- ❖ Opportunities: We are providing resources and some basic skills that can jump start their skill building

Accessibility Issues

- Font Size—we made the Font Bigger
- Radio Button Size—increased the size
- Mouse Use
- “Next Page” vs. “Submit”—now “DONE”
- User names and passwords
 - Patients now write these down
 - New tool to reset passwords online

What worked and what did not

- Patients will use the PHR survey system.
- Patients want accurate data
- Patients are receiving appropriate care especially related to ART.
- Good responses are common
- Problems of sample
- Consider differences between PHR users and non-users.

Future Data Collection

1. Do you have a computer at home?
2. Do you have your own email address?
3. How many times a week do you check their email? **Never, daily, few times per week, weekly, monthly**
4. Where do you use a computer? **Home, library, clinic, school, friend/relative, other**
5. Do you ask for assistance when you are using a computer?

Date_____

Initial_____

Patient Notes

Patient Name:_____

☐Helped patient reset Email

☐Helped patient reset myHERO username

☐Helped patient reset myHERO password

☐Patient took --_____ surveys

☐Patient picked up coupon -

☐Spent _____(min) with Patient

Notes:_____

Future work

- Allow patients to change data.
- Record data in the data base when patients change their data.
- Automate reconciliation processes
 - Simple confirmation
 - Clinician confirmation
- R18 at AHRQ for
 - Integration CES information
 - Integration and understanding of how to change treatment guidelines
- R01 at NIDA for integration of NIDAMED tool
- Improve access via cellular technology

Main Points

The study design is acceptable

Patients will enroll in a RCT

Investigators remain blinded to the data

Patients have some challenges such as maintaining their online identity


How to reconcile research data and clinical care remains an issue

We will unlikely reach our target full enrollment

Medical informatics group



Jackie So
Kelly Bryant
Lynsey Barkoff
Maurice Saah
Skip Leasure
Mitch Roberts
Tracy Nunnery
Ched Hinger
Raeni Miller
Bernard Shields

A close-up photograph of several ants on a dark, textured surface. Each ant is carrying a small, bright green, leaf-like fragment in its mandibles. The background is a soft, out-of-focus green, suggesting a natural environment. The ants are moving from left to right across the frame.

**Good ideas are not adopted automatically. They must
be driven into practice with courageous patience.**

Admiral Rickover

Demonstration

<https://myhero.sfdph.org>