

Addressing HIV Treatment Disparities Using a Self-Management Program and Interactive Personal Health Record

Kevin Fiscella, MD, MPH ¹, Jonathan Tobin, PhD², Subrina Farah, MS¹, Wendi Cross, PhD¹,
Jennifer Carroll, MD, MPH ³, Amneris Luque ⁴

¹University of Rochester, Rochester, NY

²Clinical Director's Network, New York, NY

³American Association of Family Physicians, Leawood, KS

⁴University of Texas Southwestern, Dallas, TX

PCORI ID: AD-1306-03104

HSRProj ID: 20143398

ClinicalTrials.gov ID: NCT02087956

To cite this document, please use: Fiscella K, Tobin J, Farah S, et al. 2018. *Addressing HIV Treatment Disparities Using a Self-Management Program and Interactive Personal Health Record*. Washington, DC: Patient-Centered Outcomes Research Institute (PCORI). <https://doi.org/10.25302/12.2018.AD.130603104>

Table of Contents

ABSTRACT.....	3
BACKGROUND	5
Participation of Patients and other Stakeholders	7
METHODS.....	9
Study Design.....	9
Study Cohort.....	10
Study Setting	10
Intervention.....	11
Usual Care	13
Study Outcomes	14
Procedures for Randomization and Allocation	16
Missing Data, Extreme Values, and Dropouts	16
Sample size	17
Analytical and statistical approaches	16
RESULTS	18
Aim 1: Improve PLWH's empowerment.....	21
Aim 2: Increase PLWH's receipt of evidence-based care	23
Aim 3: Improve PLWH's health.....	24
Aim 4: Reduce disparities in PLWH's empowerment	24
DISCUSSION.....	27
Decisional context	27
Study results in context	28
Implementation of Study Results	28
Generalizability.....	29
Subpopulation considerations/Heterogeneity of Treatment Effects Analysis	29
Study Limitations	29
Future Research	31
CONCLUSION	32
REFERENCES	34
APPENDIX.....	43

ABSTRACT

Background: Patient engagement is the foundation for improving health care, particularly for people living with HIV (PLWH). The Patient Activation Measure (PAM) is a widely used and validated metric for assessing patients' engagement and self-management empowerment. Patient activation is associated with improved adherence, better health outcomes, and lower costs. There is a dearth of scientific data on how to improve patient activation—particularly among individuals with the lowest activation, who are often disproportionately minority, lower-income, older, and less educated than those with higher levels of activation. The Research team used a community-based participatory research approach involving PLWH, HIV clinicians, community-based organizations, and researchers to develop a patient activation program for PLWH. Get Ready and Empowered About Treatment (GREAT) uses a smart, web-enabled device (Apple iPod) with an electronic Personal Health Record (ePHR).

Objectives: Our primary aim was to assess the impact of the GREAT program on patient activation (using PAM) among PLWH. Secondary outcomes included improvements in eHealth literacy (eHEALS), decision-making self-efficacy (DSES), patient involvement in care (Perceived Involvement in Care Scale [PICS]), patient-reported adherence to antiretroviral therapy (ART) and viral load suppression, health status/quality of life (SF-12), receipt of evidence-based care, and reductions in patient activation disparities.

Methods: We recruited 360 PLWH from 4 practices in greater Rochester, New York, and from 4 federally qualified health centers in the New York City metro area. Participants were randomized 1:1 to the GREAT intervention or control arm. Patients in the control arm received usual care from their HIV clinician during the intervention period and usual care HIV case management assistance based on patient needs and resources available in the practice. Patients in the GREAT training program received six 90-minute group-based training sessions on how to use the iPod and ePHR and how to search the web for health information, and they had a coaching session before their HIV visit. All clinicians received one 60-minute training session

focused on supporting patient empowerment. All participants received their own iPod, although participants in the control arm did not receive the iPod until 12 months postrandomization. The primary outcome was changes in the PAM. Secondary outcomes included changes in eHEALS, DSES, PICS, ART adherence and viral suppression, SF-12, and receipt of recommended care (ie, preventive screening, testing, and immunizations received during the 12 months following randomization). Participants were assessed at baseline (T0), 6 to 8 weeks postrandomization (T1), and at the end of the study (T2)—ie, 12 months postrandomization—using data abstracted from charts. We examined bivariate relationships and used mixed models that controlled for site and cohort effects.

Results: Participants who were randomized to the intervention had statistically significant improvements in PAM ($p < 0.05$). Effects were greatest among those in the lowest quartile for PAM scores at baseline. Significant improvements were also observed for eHealth literacy ($p < 0.001$) and involvement in care ($p < 0.05$). No statistically significant effects were observed for DSES, ART adherence, confidence in adherence, HIV viral suppression, SF-12, or receipt of evidence-based care. Intervention effects were similar by race/ethnicity and education level except for eHealth literacy, where effects were stronger for minority participants.

Conclusions: A multicomponent intervention improved patient activation and other empowerment-related constructs. Effects on patient activation were largest among those with lowest baseline patient activation; however, the intervention did not improve ART adherence, viral load, or receipt of evidence-based care.

Limitations and subpopulation considerations: Findings were limited by lack of full blinding of participants and research staff. Effects were largest among participants with lowest baseline PAM scores.

BACKGROUND

Patient activation is defined as “understanding one’s role in the care process and having the knowledge, skills, and confidence to manage one’s health and health care.”¹ Patient activation is critical to improving patient self-management and reducing avoidable emergency department (ED) visits and hospitalizations.² Lower levels of patient activation contribute to disparities in health care³; HIV care is a prime example. Poor and minority patients, including persons living with HIV (PLWH), report lower partnership with their clinicians,⁴ miss more office visits,⁵ ask fewer questions during their visits,⁶⁻⁸ report less confidence in self-management,⁹ and more frequently miss doses¹⁰ or stop taking their antiretroviral therapy (ART).¹¹ Patients with low levels of education and/or low income tend to know less about their medications,¹² report fewer benefits from cancer screening,¹² and report less involvement in cancer screening decisions.¹³ In other words, social disadvantage likely undermines elements of patient activation—eg, knowledge, skills, and confidence—and is associated with less access to resources to support self-management.

Prior studies have found that low patient activation among PLWH contributes to disparities in adherence^{14,15} and viral suppression,^{16,17} and ultimately to disparities in HIV treatment outcomes,¹⁸⁻²⁰ including hospitalizations and mortality.^{21,22} Death from HIV-related causes is among the top 10 leading causes of death among blacks and Latinos aged 20-54 years.²³ Among blacks aged 35-44 years, HIV ranks in the top 5 causes of death.²³ We hypothesize that addressing disparities in patient activation provides one means for mitigating the impact of these health outcomes on PLWH.

For many people, patient activation depends on access to relevant web-based information—ie, disease-specific information and data on one’s personal health information, which are typically available through vetted health information websites and electronic portals that have become part of most electronic health records (EHRs) systems, respectively. Evidence is weak that availability of patient portals to EHRs alone, or even use of handheld electronic personal health records (ePHRs) alone, improves self-management.^{24,25} Access to ePHRs must be coupled with targeted interventions that address patient activation, yet relatively little is known about how to improve patient activation, including use of PHRs among

PLWH.^{26,27} We were unable to identify any randomized controlled trials that tested interventions designed explicitly to improve patient activation among PLWH.

Our conceptual model for improving patient activation is based on the Capability, Opportunity, Motivation and Behavior model for behavior change.²⁸ Patient activation requires *motivation* to assume greater involvement in one's own health care. It requires *capability*, including requisite knowledge and skills as well as *confidence* that one can take greater ownership. And it requires a supportive opportunity or context, including access to relevant *online information* and *digital tools*.^{29,30} Motivation toward a goal is based on perceived value and expectation for success in achieving it. Many socially disadvantaged patients have not had role models for patient activation, much less experience with how activation might be viewed as beneficial. Many socially disadvantaged patients lack access to reliable sources of health information beyond brief medical encounters. The experience of being disadvantaged and socially disempowered undermines self-efficacy, particularly during medical encounters where social distance is large (eg, between a person living in poverty and a physician).³¹ Last, the digital revolution in health care could leave older, lower-income, and less-educated people behind, creating worse disparities.³² Age, education, and income are each associated with access to a broadband connection,^{33,34} going online for health information,^{35,36} knowledge of computers and smart devices, and use of online patient portals.^{36,37} Addressing disparities in patient activation requires improving internet access (eg, through devices that can access the web via free WiFi or low-cost data plans) and providing disadvantaged groups with the knowledge, confidence, and skills necessary to go online when access is available.

The Get Ready and Empowered About Treatment (GREAT) project directly targeted these drivers of patient activation. It addressed motivation through a unique blend of external incentives (smart devices) and internal incentives; the latter were based on group work that promotes patient perceived autonomy (ability to enact one's own goals and preferences), competence (learning new skills), and relatedness (co-learning and assisting other group members). The project imparted knowledge through group discussion and promotion of highly reliable sources of information. Training addressed confidence through small achievable steps in proficiency, and scaffolding supported small next steps in the learning process.

A smart device was provided, and, notably, participants were taught to use an ePHR. The project leveraged the growing availability of portals by training patients to access high-quality health information and to learn how to transfer their information to their own ePHR for personal use. National data show that patients, particularly those with low income, low education, and chronic conditions, report greater benefits from having access to their ePHR.³⁸ The study aims are shown in Table 1.

Table 1. Study Aims and Hypotheses

Aim 1: Improve PLWH's empowerment

H 1.1: We will improve patient activation; decision-making ability; and perceived knowledge, comfort, and skills at finding, evaluating, and applying electronic health information to health problems.

H 1.2: We will improve clinicians' communication skills as perceived by PLWH.

Aim 2: Increase PLWH's receipt of evidence-based care

H 2.1: We will improve patient confidence in adhering to combination antiretroviral treatment (cART), self-reported adherence to cART, and HIV viral suppression (undetectable viral load).

H 2.2: We will increase receipt of evidence-based clinical preventive services.

Aim 3: Improve PLWH's health

H 3.1: We will improve mental, social, and overall health.

Aim 4: Reduce disparities in PLWH's empowerment (heterogeneity of treatment effects analysis)

H 4.1: We will produce the greatest improvement in activation for those with lowest baseline activation.

H 4.2: We will observe comparable improvements by race, ethnicity, and education.

PARTICIPATION OF PATIENTS AND OTHER STAKEHOLDERS

Initially begun in August 2009, our project was grounded in the principles of community-based participatory research (CBPR). From its inception, patients and stakeholders have been active partners in each phase of the project.^{39,40} In Rochester, New York, this partnership has included 4 PLWH, 4 HIV medical directors, and representatives from 2 HIV service organizations, in addition to 2 outreach workers and clinicians and researchers from a practice-based research network (PBRN). In New York City (NYC), Clinical Directors Network (CDN, www.CDNetwork.org), a primary care PBRN and AHRQ-designated Center of Excellence (P30) for primary care practice-based research and learning, has worked closely with the clinical and administrative staff, including the medical and nursing directors and HIV and peer educators at

the 2 federally qualified health centers (FQHCs) that participated in the NYC pilot, and the current proposal is based on feedback from their active engagement as well as from other clinicians who participated in the CDN-PBRN.

These partnerships involved cross-training between members in CBPR approaches as well as research and methods of collaboration, including data sharing, decision making, and revenue sharing. The meeting facilitator ensured that every member had the opportunity to speak and contribute. The group agreed that all aggregated data would be distributed among members and that key decisions, including next steps in the research project, would be decided by the group. Each participating organization was compensated for use of space, promotion of projects, and staff time; individual patient stakeholders were compensated based on time contributed to the project. Meetings were held quarterly at 7:00 AM at a convenient location and utilized both in-person (Rochester) and online (CDN, NYC) participation.

The original idea for the proposal came from a PLWH who pointed out that lack of information and limited access to their test results data, specifically their HIV viral load, represented barriers. Our patient partners further noted that many patients declined offers for printouts of test results due to fear of a breach of confidentiality (ie, a friend, family member, or acquaintance may inadvertently see printed personal health information). Our patient partners initially suggested use of a secure, password-protected electronic device to store patient information. The partnership considered various options, including use of standard cellphones (most lack the ability to run suitable applications), use of smartphones (prohibitive initial cost and need for wireless telephone contracts that many patients would not qualify for nor afford), and standalone devices (need for separate device beyond standard cellphone). After weighing these considerations, the partnership decided that the iPod Touch would be the best option because it has many of the features of smartphones minus the expensive service contract, is web-accessible at free Wi-Fi hotspots, and could access and utilize the full range of apps and websites as a smartphone. Notably, this device was chosen by our CBPR group years before the study began and before widespread availability of other electronic web-enabled devices.

Patients and stakeholders have been involved throughout the project and are now

engaged in developing a proposal to PCORI for dissemination and implementation among community-based organizations serving PLWH. Patients wanted training to enhance their ability to self-manage their condition and communicate more effectively with their clinicians. We adopted an iterative, user-centered approach to designing the training and designing the ePHR application. Specifically, we collected both quantitative and qualitative data from training participants during each step of the process and used those data to inform next steps. Notably, we presented findings from each phase to our patient partners, clinicians, and other stakeholders for further input. This approach guided the type and frequency of training, design of the app, research questions, and outcome measures.

Our patients and stakeholders were interested in the following primary research question: Will our intervention improve empowerment and engagement in patients relative to their current, usual treatment? Thus, our overarching aim was to compare the effectiveness of our multimodal intervention with usual care. This decision was also based on the absence of existing patient activation interventions in routine practice.

METHODS

Study Design

To guide us in assessing a range of study designs on their relative strengths and weaknesses, we used PCORI Methodology Standards.⁴¹ Our primary goal was to generate findings with real-world implications—ie, how to empower PLWH while minimizing bias from unmeasured confounding. Thus, we selected a pragmatic randomized controlled trial as our design. It allowed us to compare preassessments and postassessments of participants randomized to the intervention (experimental treatment) with preassessments and postassessments from participants randomized to usual care (comparator = usual care). Given the nature of our intervention—including its reliance on training and specific tools—the risk for contamination between participants was deemed small. We considered other designs, including randomizing by practice site (cluster randomized trial), stepped wedge randomized trial, and staggered enrollment trials, but did not choose these designs due too few clusters, data collection burden, and a relatively short time frame (3-year project). To maximize

generalizability, we opted for a pragmatic trial that employs broad “real-world” inclusion criteria for participants. We adopted inclusive recruitment methods and tracking enrollment by subgroup—eg, black, Latino, white non-Latino, and highest educational level—to minimize enrollment bias in our sample. Without resorting to oversampling, we enrolled participants who mirrored the patient population in the participating practices and NYS more broadly.

Participants in both arms received the smart device (iPod Touch); however, only participants in the experimental arm received the device and were trained on its use during the trial. Usual care/control arm participants received the device and instructions on its use after the T2 follow-up measures were obtained (2-4 weeks following the participants’ subsequent HIV visit). The study was approved by the University of Rochester Human Subjects Review Board and CDN IRB, and it was registered at ClinicalTrials.Gov (NCT02165735).

Study Cohort

Our eligibility criteria were broadly inclusive to reach a broad sample of typical patients living with HIV. We included patients with confirmed HIV diagnoses who were at least 18 years of age and who received care at a participating site. We excluded those who were unable to provide informed consent or had insufficient English proficiency to participate. We opted for direct recruitment of participants through onsite, face-to-face discussions at the time of patient visits and/or practice outreach to minimize any bias from differences in reading skills, social networks, or referrals. We adopted slightly different approaches, depending on the practice context. In Rochester, the clinician/designee introduced the study and referred interested patients to the research assistant (RA). The RA then met privately with potential participants to review the study protocol and obtain consent from those interested. In NYC, we used phone calls, based on patients identified from medical records, and intercepted patients who presented for visits with their HIV clinician during dedicated sessions for HIV care.

Study Setting

Rochester sites included 3 dedicated HIV practices and 1 FQHC with a large HIV population. The HIV practices included 2 hospital-based HIV practices and a practice largely

devoted to the needs of HIV-positive and sexual minority individuals. The sites in the greater NYC area were 4 CDN-member FQHCs with large HIV-positive populations.

Intervention

We designed an intervention to promote patient activation among PLWH by targeting key drivers (motivation, knowledge, skills, confidence, and technology). The intervention consisted of (1) a customized ePHR for PLWH using an iPod Touch to access the internet, (2) six 90-minute group-based training sessions on use of the iPod and the ePHR and on searching the web for health information, (3) a previsit coaching session, and (4) clinician training in supporting patient empowerment. Sixty-five participants who required extra help (or missed a session) met individually with trainers to catch up, for a total of 72 extra sessions.

Handheld device. We selected the Apple iPod Touch® based on its widespread availability and adoption, versatility (number of applications, web-enabled), intuitive interface/usability, relatively low cost (\$199), no requirement for phone or internet service provider contract, and overall desirability and “coolness” factor.

ePHR. We loaded each device with our customized ePHR, developed for PLWH, named UrHealth. We had previously created this app from a user-centered design with one-on-one interviews and then formally piloted it before undertaking this study; we did not conduct further usability testing during the current study. Key features include (1) drop-down menus of common HIV medications with accompanying pill photographs; (2) common lab tests with brief, understandable explanations; (3) a setting to create reminders for appointments and taking and refilling medications; (4) a personalized “prompt list” of potential questions for patients to ask their clinicians. These questions are generated from data the patients enter into their devices, such as date of birth. For example, if the patient is less than 26 years old, he or she will be prompted to ask about the HPV vaccine (unless he or she has already entered dates of its receipt). The patient can personalize these prompts by prioritizing them and, most important, to augment them with their own formulated questions. Participants provided written consent for us to track use of the UrHealth App.

Group training. The iPod represented a potential incentive or “hook” to encourage

participants to enroll. We explicitly targeted key *intrinsic motivational factors* (autonomy, competence, and relatedness) as ways to engage patients during the groups. Each of the six 90-minute sessions focused on development of a basic eHealth competency by encouraging patient practice, mutual support and assistance, and celebration of successes. Participants themselves entered the data; trainers provided guidance and encouraged participants to bring their device to their appointments and confirm data they entered with their clinicians, although no direct digital data exchange took place between the practice EHR and the ePHR. Thus, clinicians had access only when participants specifically showed them the device. Key tasks are summarized in Table 2.

Table 2. Key Tasks for Group Training

- **Project overview, value affirmation exercise, and basic use of the device** (turning on and off, password, settings)
- **Basic training in use of ePHR** (recap and introduction to features, password, backup, importing contacts)
- **Advanced training in use of ePHR** (reminders, data entry, confirmation of data, to-ask list)
- **Communication and use of websites** (training in formulating, prioritizing, asking questions, bookmarking high-quality websites)
- **Communication and health apps** (role-playing challenging situations, using ePHR during visit, downloading relevant health apps)

Previsit coaching. After participants in the intervention arm completed their last session, a health coach met with each patient before his or her next HIV office visit. This one-time individual coaching session was designed to reinforce skills learned during the group training and to prepare patients to be engaged in their office visit with their clinician. A training manual and fidelity checklist addressed this one-on-one session (see Appendix). Key tasks for the previsit coaching session are summarized in Table 3.

Table 3. Key Tasks for Previsit Coaching

- **Bring iPod/ePHR** (reminding the patients bring their iPod to their patient coaching session and to their subsequent doctor visit)
- **Preparation of questions** (ensuring that the patient has identified and recorded in the iPod key questions to ask the clinician)
- **Application and rehearsal of skills** (coaching the patient to role-play asking his/her questions)

Clinician training. We trained all clinicians to engage patients in the visits through one 60-minute, educational “lunch and learn”—ie, a CME-accredited session that addressed the

purpose of the project and basic clinician behaviors to facilitate empowerment. We used the Invite-Listen-Summarize model⁴² of communication and incorporated evidence-based communication skills.⁴³⁻⁴⁵ We employed training approaches used in previous studies.⁴⁶⁻⁴⁸ These approaches are supported by systematic reviews of randomized controlled trials of clinician training.^{49,50} We demonstrated the behaviors via brief videos with standardized patients (Table 4).⁵¹ We believe these approaches can help foster greater uniformity in clinician receptivity to activated patients, even though clinicians may be exposed to patients with different levels of activation.

Table 4. Key Tasks for Clinician Training

- **Encourage the patient to use his or her ePHR** (If/when patient brings his or her iPod to the visit).
- **Invite the patient to ask questions** (including asking the patient, “Is there something else?” and helping the patient to prioritize issues during visit).
- **Listen to the patient** (without interrupting and respond empathically).
- **Summarize visit** (at end and confirm patient’s understanding).

Steps to Ensure Fidelity. We developed a detailed training manual (see Appendix) for training professional staff and peers to conduct the training sessions. We conducted train-the-trainer sessions followed by remote videoconferencing training. Sessions emphasized enthusiasm, active engagement of the group through questions and sharing, staying on task and time, and ensuring that all members can rehearse a particular skill during the session. We assessed fidelity using an observation checklist based on key process and content elements for each session. Trained observers checked for fidelity criteria during in-person observations. We retrained trainers when fidelity drift occurred.

Usual Care

Consistent with features for a pragmatic trial, we did not adopt an attention control; instead, patients randomized to the control arm (usual care) received care according to the practice’s guidelines. Control patients received the same smart device as did those in the intervention; however, they were not trained in using it, nor did they receive the ePHR app during the study. Most practices had case managers who assisted patients with addressing access barriers and promoted adherence. Case managers were available to all patients regardless of study arm, although their availability differed by site.

Study Outcomes

Data were collected at baseline T0 (immediately prior to randomization) and at T1 (8 weeks postrandomization and shortly after the activation training), T2 (2-4 weeks following the participants' subsequent HIV visit), and T3 (12 months postrandomization). RAs administered survey questions to participants at T0, T1, and T2. RAs abstracted medical record data at T3. Neither participants nor RAs were fully blinded.

Patient empowerment

Our primary outcome, the Patient Activation Measure (PAM), was chosen by our patients and stakeholders. We used the short-form PAM, a 13-item scale that assesses patient knowledge, skill, and confidence for self-care.⁵² Raw scores are transformed from 0 to 100. PAM is reliable (Cronbach's alpha = 0.91 with a Rasch person statistic = 0.81)⁵² and has previously been used to assess patient activation among PLWH.^{26,53,54} Notably, the higher PAM levels are prospectively associated with meaningful outcomes such as improved adherence and lower ED use by PLWH.² We aimed to capture related dimensions including eHealth literacy (eHealth Literacy Scale [eHEALS], Cronbach alpha = 0.94),^{55,56} patient involvement in care (Patient Involvement in Care Scale [PICS], Cronbach's alpha = 0.73),⁵⁷ and patient self-confidence in health care decision making (Decision-making Self-Efficacy Scale [DSES], Cronbach's alpha = 0.92).⁵⁸

Using a structured case report form of explicit criteria, trained RAs performed chart abstraction for viral loads and evidence-based preventive care (see Appendix). When a screening, immunization, or test was absent from the record, it was coded as not performed. The timing of data collection is summarized in Table 5.

Table 5. Study Measures, Data Source, and Timing

Construct (Hypothesis)	Measure	Data type source	Collect-ion Time Points
Participant characteristics			
Demographics	Standardized questions	Survey	T0
Computer experience	Standardized questions	Survey	T0
Health history	Standardized questions	Survey	T0, T3
Aim 1 (Empowerment)			
Patient activation (H1.1)	Patient Activation Measure: PAM ^{52,59}	Scale	T0, T1 T2
Decision making (H1.1)	Decision Self-Efficacy Scale: DSES ⁵⁸	Scale	T0, T1 T2
eHealth literacy (H1.1)	eHealth Literacy Scale: eHEALS ^{55,56}	Scale	T0, T1 T2
Involvement in care (H1.2)	Perceived Involvement in Care: PICS ⁵⁷	Scale	T0, T1 T2
Aim 2 (Evidence-based care)			
HIV adherence self-efficacy (H2.1)	HIV Adherence Self-Efficacy Scale: ASES ⁶⁰	Survey	T0, T1 T2
Adherence to cART (H2.1)	Past week adherence ⁶¹	Survey	T0, T1 T2
HIV viral load < 50 (H2.2)	HIV viral load (both actual level; and whether undetectable or not)	Chart abstraction	T0, T3
Evidenced-based preventive care	Index for preventive care ^{62*}	Chart abstraction	T0, T3
Aim 3 (Health)			
Physical and mental health/quality of life (H3.1)	SF-12 ⁶³	Scale	T0, T1 T2
Aim 4 (Moderators)			
Low activation (H4.1)	PAM and eHEALS (< median)	Scale	T0
Minority race/ethnicity (H4.2)	Standardized questions	Survey	T0
Low education (4.2)	Standardized questions	Survey	T0
Clinician patient centeredness	Instrument on Doctor-Patient Communication Skills (IDPCS). ⁶⁴	Scale	T0

T0 = baseline

T1 = 8 weeks postrandomization,

T2 = 2 to 4 weeks following HIV visit after T1

T3 = 12 months postrandomization

*We created a preventive care index for each participant by assigning 1 point of each intervention he or she received postrandomization divided by the total number of interventions for which he or she was eligible.

The possible range of the key scales is shown in Table 6.

Table 6. NAME OF MEASURE	RANGE OF SCORES
Patient Activation Measure [PAM]	0-100
eHealth Literacy Scale [eHEALS]	8-40
Decision Self-Efficacy Scale [DSES]	0-100
Perceived Involvement in Care Scale [PICS]	8-40
Instrument on Doctor Patient Communication Skills [IDPCS]	19-95
Short Form Health Survey: Physical and Mental Health [SF-12]	0-100 (per scale)
HIV Adherence Self-Efficacy Scale [ASES]	0-150

Procedures for Randomization and Allocation

Our study statistician generated sequential identification (ID) numbers using computer-generated random numbers stratified by site (Rochester or NYC). Prior to participant enrollment, 360 sequentially numbered, opaque, sealed envelopes were created. Each envelope contained the IDs on the outside of the envelope and experimental arm assignment (intervention or usual care) on the inside. The RA opened the envelopes sequentially, only after the participant had completed the baseline (T0) assessment, so that the arm assignment was concealed from the RA prior to the T0 assessment.

Missing Data, Extreme Values, and Dropouts

We took steps to minimize missing data by ensuring that participants responded to all items. We obtained multiple contacts' telephone numbers from participants and made repeated efforts to track them down. Our analysis strategy relied on mixed-effects models of all available observations from participants. This approach optimizes use of nonmissing data under the same ignorable missing data assumption ("missing at random" [MAR]) that underlies the validity of standard multiple imputation procedures.⁶⁵ We used multiple imputation based on all respondents when fewer than half of items were missing from a particular scale. In those rare (< 1%) instances where half or more of items were missing, the scale was treated as missing. We tested for the MAR assumption using Little's test.⁶⁶ We also created dummy variables for whether the variable was missing and assessed associations with variables. We conducted sensitivity analyses in which we excluded participants who responded with consistent extreme values to scales.⁶⁵ For the main effects analysis, we used an intent-to-treat

approach such that all participants were analyzed based on the arm to which they were initially assigned, regardless of their level of participation in the intervention. All analyses were conducted using SAS version 9.4 (Cary, NC).

Sample size

For H 1.1–H 3.1, we estimated detectable difference using the method described by Donner and Klar,⁶⁷ a significance level of 0.05, and a minimum power of 80%. The intraclass correlation (0.0207) was estimated from our pilot data and is consistent with other studies.⁶⁸ Based on planned enrollment of 360 participants and an estimated 15% dropout rate, we calculated power to detect a standardized effect size of 0.51 (difference in mean/standard deviation for the full sample) for each of the measures in Aims 1 to 3. An effect size of 0.35 for PAM is associated with statistically significant although modestly clinically higher ART adherence and viral load suppression.⁵³

For H 4.1 and H 4.2, we ran Monte Carlo simulations to determine treatment interaction effects. Based on the simulated data, we ran generalized linear model procedures and observed 80% power to detect a difference of 3.7 in PAM between (theoretical range 1-100) low- and high-activation groups based on a sample size of 300.^{69,70}

Analytical and statistical approaches

Our general approach was to compare the 2 study arms in terms of changes in the dependent variable from baseline, using separate models for patient activation, eHealth literacy, and decisional self-efficacy outcomes using GEE models that controlled for clustering with site (Rochester and NYC) and within training cohort. In our mixed models, we included study arms; cohort; timeline; race; ethnicity; gender; age; computer use; education; familiarity with an iPod, iPad, or iPhone; income; internet use; and marital status as covariates. We followed a forward stepwise selection of significant factors in the final model from the full model. All models were adjusted for any potential confounders, including arm; cohort; time; race; ethnicity; gender; age; prior general computer use; education; familiarity with an iPod, iPad or iPhone; income, internet use; and marital status. To assess the intervention effect, we

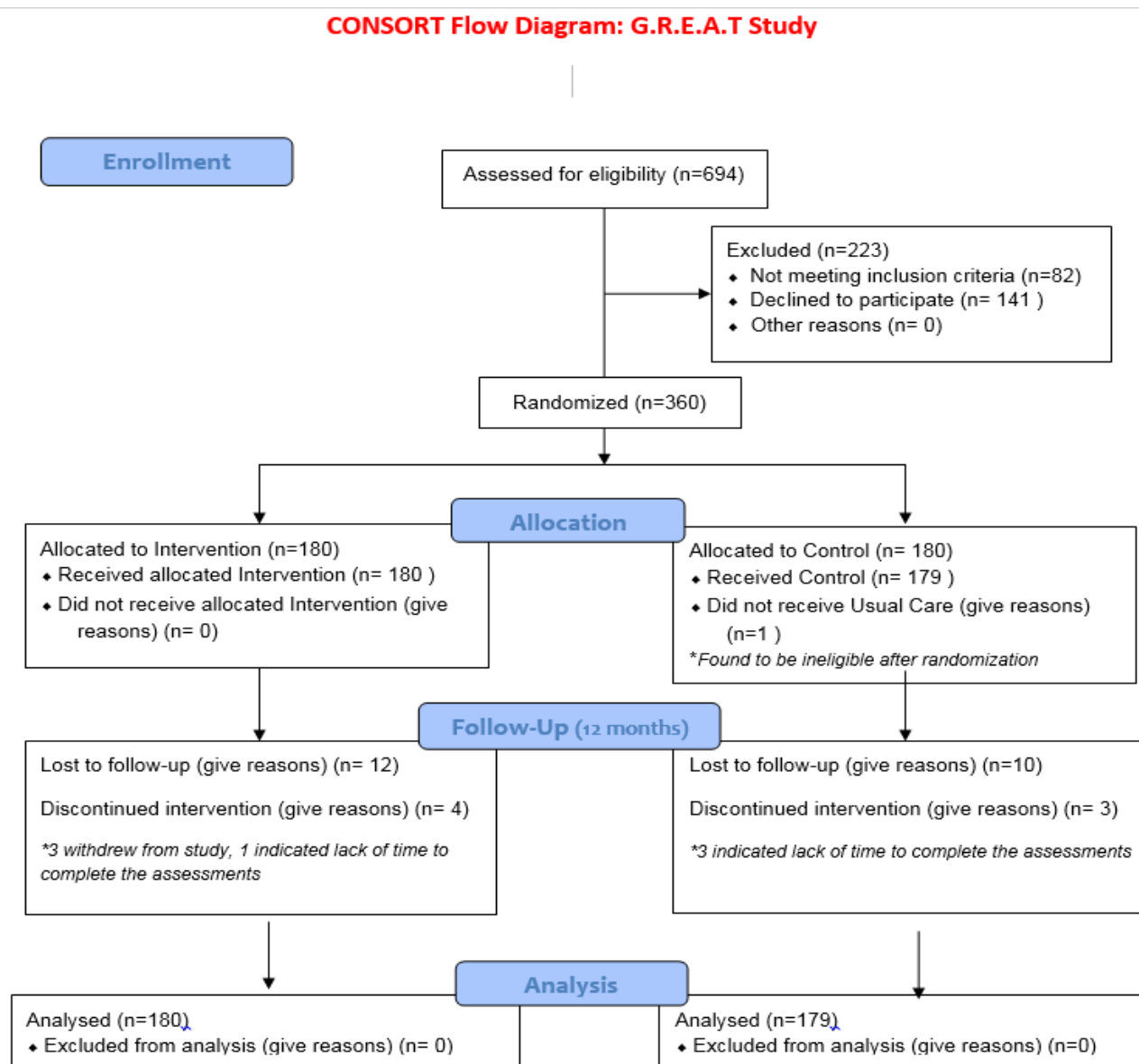
entered experimental arm as an interaction term with time (arm x time). We imputed missing values (< 1%) using multiple imputation.^{65,71} To assess the potential for extreme values to affect the results, we conducted sensitivity analyses in which we excluded participants who reported consistently extreme values for a particular scale. In secondary analyses, we used the same statistical models using a “per protocol” analyses among participants who used the UrHealth app at least once in the 6 months following their group training.

To address Aim 4, **which represents our heterogeneity of treatment effects (HTE) analysis**, we entered interaction terms into the models with treatment arm. Given our focus on addressing disparities in social advantage—eg, low health literacy, minority race/ethnicity, and low education—we included prespecified interaction terms based on lowest quartile cutoffs for activation and eHealth literacy in addition to minority race/ethnicity and low education. When the interaction term was significant ($p < 0.05$), we conducted stratified analyses to assess the impact of the intervention on these subgroups. We also assessed whether clinician behavior affects outcomes, by entering an interaction term for clinician behavior using the Instrument on Doctor-Patient Communication Skills,⁶⁴ measured at baseline (T0) using a median cutoff.

RESULTS

A total of 360 participants were enrolled between August 2014 and March 2016, including 240 from the greater Rochester, New York, area and 120 from the greater New York City area. A total of 694 participants were screened for eligibility, 471 met eligibility criteria, and 360 were randomized (see consort diagram, Figure 1). All 180 patients randomized to the intervention arm were considered for the final analyses. From the control arm, 179 participants were considered for the final analyses, and 1 person was excluded after they were later found to be ineligible for the study due to previous participation in the GREAT pilot. The characteristics of participants in each arm are summarized in Table 7. There were no statistically significant differences between the 2 arms.

Figure 1. Participant Flow Through the Study



Participants' baseline demographics were well matched between the intervention and control arms (Table 7), and 84% of intervention participants attended at least 1 group training session. The mean number of sessions attended (not including individual makeup sessions) among all participants in the intervention was 3.6 out of 6; 3 in 4 participants (76%) attended a previsit coaching session.

We assessed use of the UrHealth app by identifying those using the app during the training sessions, among those assigned to the intervention arm and by assessing frequency of

login and screen use. We were able to identify 133 participants (74% of those in the intervention) who used the app once ever and 109 participants (61% of intervention participants) who used the app at least once in the 6 months following their training (control participants did not have access to the app during the study). The 109 participants used the app post-training for a mean of 18 times (a mean usage time of 131 minutes during the 6-month period following their group training). In order of frequency, the most commonly opened screens were tests, events, and the to-do list (which included the question prompts).

Table 7. Baseline Characteristics of Study Participants			
Characteristic	Intervention (n = 180)	Control (n = 179)	P value
Age, mean (SD)	51.7 (10.7)	51.2 (11.3)	0.69
Sex (%)			0.15
Male	62.2	56.4	
Female	37.8	41.9	
Transgender	0	1.7	
Race (%)			0.11
American Indian/Alaska Native	0.6	0	
Asian	0	0	
White	23.9	20.7	
Black or African American	54.4	49.7	
Native Hawaiian or Other Pacific Islander	0	0	
More Than One Race	10.0	6.7	
Other	8.9	16.7	
Unknown or Not Reported	2.2	6.7	
Latino Ethnicity (%)	20.0	26.3	0.16
Insurance Type (%)			0.70
Private	7.2	8.4	
Medicare	28.3	24.0	
Medicaid	77.8	77.1	
ADAP	11.1	13.4	
Other	7.2	6.7	
None	3.3	1.1	
Income (%)			0.88
\$0 to \$999	70.0	67.6	
\$1000 to \$1999	21.1	23.5	
\$2000 and over	8.9	8.9	
Education (%)			0.66
Less than high school	28.9	31.3	
High school diploma / GED or equivalent	31.1	28.5	

Some college (no degree) or technical school	20.6	24.0	
Associate degree	10.6	6.7	
Bachelor's degree or higher	8.9	9.5	
Frequency of computer use (%)			0.79
Missing	0	1	
Never	25.1	25.1	
Frequency of internet use (%)			0.23
Number missing	0	2	
Never	17.3	23.0	
Familiarity with an iPod, iPad, or iPhone			0.89
Number missing	0	2	
Never heard of it	1.1	1.7	
I've heard of but haven't used one	53.6	48.9	
I've used one a few times	18.4	18.5	
I previously owned one	12.3	14	
I currently own one	14.5	16.9	
No. Visits/Yr.	5.6 (3.5)	5.4 (3.4)	0.66
Undetectable Viral Load (%)	76.7	75.4	0.78
Baseline Outcome Measures, mean (SD)			
PAM	72.15 (16.70)	70.78 (15.57)	0.21
eHEALS	28.53 (7.75)	27.27 (8.52)	0.14
DSES	91.05 (12.63)	90.76 (12.03)	0.41
PICS	30.58 (5.89)	30.17 (5.59)	0.25
IDPCS	85.07 (13.50)	82.63 (17.00)	0.07
ASES	101.27 (18.49)	100.84 (19.54)	0.58
SF-12 (mental)	45.93 (11.15)	45.99 (11.04)	0.52
SF-12 (physical)	43.15 (12.76)	44.80 (12.17)	0.89

***Abbreviations:** PAM, Patient Activation Measure; EHEALS - eHealth Literacy Scale; DSES - Decision Self-Efficacy Scale; PICS - Perceived Involvement in Care Scale; IDPCS - Instrument on Doctor Patient Communication Skills; SF-12 - Short Form Health Survey: Physical and Mental Health; ASES - HIV Adherence Self-Efficacy Scale

Aim 1: Improve PLWH's empowerment

H 1.1: We will improve patient activation (PAM); decision-making ability (DSES); and perceived knowledge, comfort, and skills at finding, evaluating, and applying electronic health information to health problems (eHEALS).

Our primary study outcome was patient activation as measured by PAM. Patient activation at baseline was similar for intervention (72.1 ± 1.34) and control (70.8 ± 1.36) arms ($P > 0.05$). In mixed models that controlled for patient characteristics and clustering of patients by

cohort and by site (all outcomes discussed are presented in Table 8), patient activation increased more in the intervention arm than in the control (73.35 ± 1.13 versus 70.53 ± 1.14 ; $p < 0.027$). In sensitivity analyses, results remained significant when extreme values were omitted. In the final mixed model for changes in PAM, cohort group, education, and familiarity with an iPod/iPad/iPhone were statistically significant predictors of improvement in PAM.

Results were also statistically significant for mixed models that included potential confounders for eHealth literacy, patient perceptions of involvement in care, and patient perceptions of clinician communication (ie, Instrument on Doctor-Patient Communication Skills [IDPCS]). Each, except for the IDPCS, remained statistically significant after further adjustment for multiple comparisons. Again, exclusion of extreme values did not alter the results. Effects were not significant for adherence self-efficacy, patient-reported adherence, or improvements in viral load. There was no significant change in mental or physical health or receipt of evidence-based care.

H 1.2: We will improve clinicians' communication skills as perceived by PLWH (PICS).

We observed marginally statistically significant improvement in patient perceptions of clinicians' communication skills ($P = .049$; Table 8), although this was no longer statistically significant after adjusting for multiple comparisons.

Table 8. Effect of the GREAT Intervention on Study Outcomes

Table 1. Effect of the eHEALS Intervention on Study Outcomes								
Outcomes	Intervention+		Control+		Coefficient	95% CI		P value
	Mean	SD	Mean	SD	Estimates	Lower	upper	
Measures								
Hypothesis 1.1								
(Primary)								
PAM‡	73.35	1.13	70.53	1.14	2.82	0.32	5.32	0.0271
Hypothesis 1.1 (Secondary)								
eHEALS‡	29.81	1.45	27.67	1.42	2.67	1.38	3.95	< .0001
DSES‡	91.89	0.86	90.81	0.87	1.09	−0.82	3.00	0.2631
PICS‡	33.74	0.94	32.47	0.90	1.27	0.41	2.13	0.0038

Hypothesis 1.2								
IDPCS	85.06	1.24	83.49	1.25	3.18	0.01	6.35	0.0490
Hypothesis 2.1								
ASES	102.8	1.08	103.1	1.07	-0.33	-3.26	2.60	0.8251
	0		3					
Self-reported								
Adherence	89.33	1.09	89.90	1.09	-0.56	-3.44	2.32	0.7014
Undetectable viral load	87%	3.1%	86%	3.1%	0.00	-0.06	0.07	0.9113
Hypothesis 2.1.								
Evidence-based Preventive care	0.35	0.01	0.35	0.02	-0.01	-0.05	0.05	0.9937
Hypothesis 3								
SF-12 (mental)	46.38	0.73	46.99	0.73	-0.61	-2.29	1.08	0.4787
SF-12 (physical)	44.83	0.71	45.13	0.72	-0.30	-2.29	1.66	0.7625
Hypothesis 4.1								
PAM: Low PAM*Arm								0.0175
Hypothesis 4.2								
PAM: Minority Race*Arm								0.9998
PAM: Low Education*Arm								0.1504
PAM: IDPCS*Arm								0.5389
eHEALS: Minority Race*Arm								0.0275
eHEALS: Low Education*Arm								0.5509

+Data are means (SD) except where noted.

*Percentage of patients with testing whose viral load was undetectable.

‡ Significant between arms at $\alpha = 0.05$ (all remained significant after Bonferroni correction for secondary measures [$P < 0.0047$] except IDPCS, which was no longer statistically significant

†For mixed-model calculation, arms, cohort, timeline, race, ethnicity, gender, age, computer use, education, familiarity with an iPod/iPad/iPhone, income, internet use, and marital status have been considered.

Aim 2: Increase PLWH's receipt of evidence-based care

H 2.1: We will improve patient confidence in adhering to combination antiretroviral treatment (cART), self-reported adherence to cART, and HIV viral suppression (undetectable viral load).

Results were not statistically significant for patient confidence in adhering to cART,

patient self-reported adherence to cART, or undetectable viral load (which improved in both arms). We conducted secondary analyses among participants with a detectable viral load at baseline and among participants who reported missing at least 1 dose of their ART in the past week. Neither of these subgroup analyses showed significant effects. We examined changes in viral load among participants who used the app at least once and found no effects for the intervention compared with control. In secondary analyses, we explored absence of effects by examining the relationships between PAM and adherence and adherence and viral load. We found statistically significant but weak correlations between PAM and self-reported adherence ($R = 0.21$, $P < .0001$) and between self-reported adherence and undetectable viral load ($R = 0.15$, $P < .01$). These findings suggest that the path between PAM and viral load, while present, is too weak to show detectable effects in our analysis (see Table 8 for all outcomes).

H 2.2: We will increase receipt of evidence-based clinical preventive services.

There was no statistically significant improvement in overall receipt of evidence-based preventive services (Table 8); a sensitivity analysis that restricted the intervention arm to participants who used the app at least once also failed to show statistically significant effects.

Aim 3: *Improve PLWH's health*

H 3.1: We will improve mental, social, and overall health.

There was no statistically significant improvement in mental or physical health status (Table 8).

Aim 4: *Reduce disparities in PLWH's empowerment*

H 4.1: We will produce the greatest improvement in activation for those with lowest baseline activation.

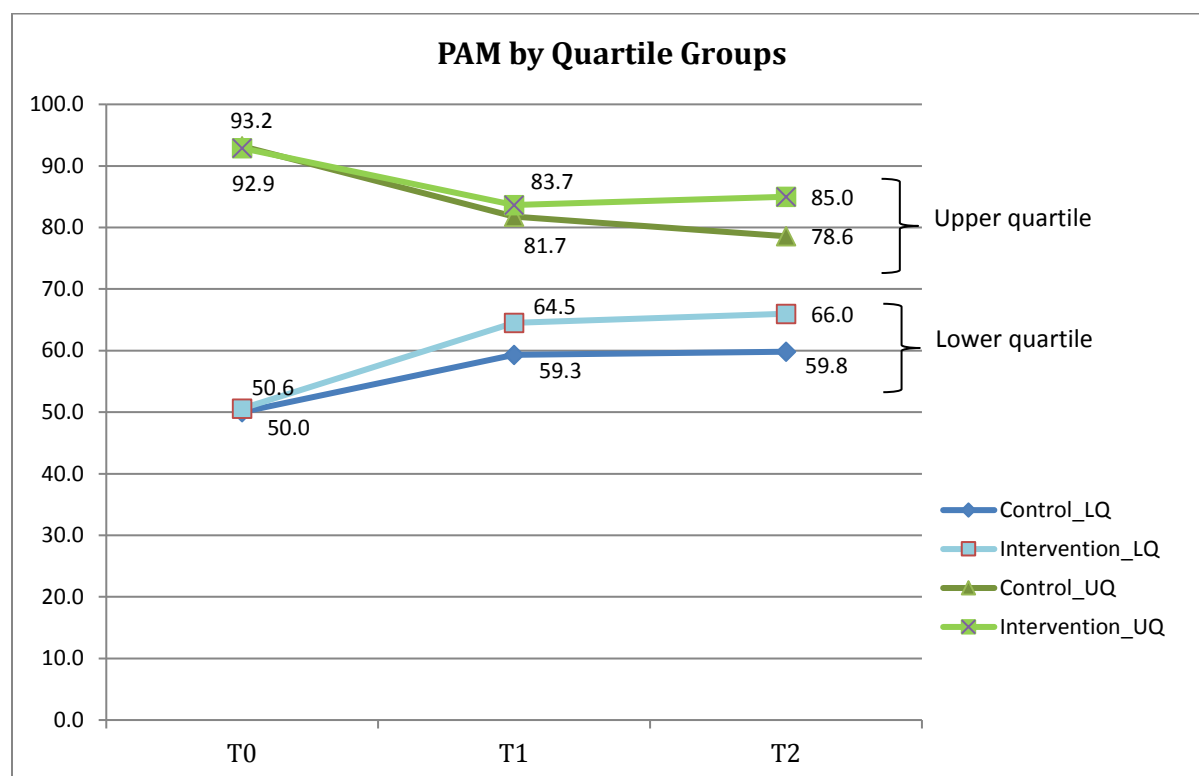
Participants with PAM scores in the lowest quartile showed statistically significant improvements when receiving the intervention (Table 8). The relative magnitude of these improvements is shown in Figure 2. In a mixed model of the subgroup of patients in the lowest quartile of PAM scores ($n = 90$), the intervention resulted in an increase in PAM of 3.9. In contrast, effects were smaller (3.3) for those in the upper 3 quartiles and results did not reach

statistical significance. The lowest quartile approximates persons who scored at level 1 and 2 for PAM. While regression to the mean likely contributes to greater *within*-group improvements—ie, high-quartile and low-quartile groups—it is unlikely to explain the smaller differences *between* groups—ie, between the intervention and control arms. Last, we examined a 1-stage improvement in PAM among participants who scored at PAM stage 1, where the impact on outcomes is likely to be greatest. The results showed that the intervention was associated with an improvement to higher stage (odds ratio: 2.10; 95% CI, 1.08-4.07).

Per-protocol analysis

We repeated all the analyses among participants who used the app at least once post-training. In mixed models, we observed larger effects (often double) among app users than among those observed in the full analysis (see Appendix). However, statistically significant effects were the same as in the intent-to-treat analysis—ie, statistically significant effects only for patient activation, eHealth Literacy, and involvement in care.

Figure 2: PAM by Quartile Groups

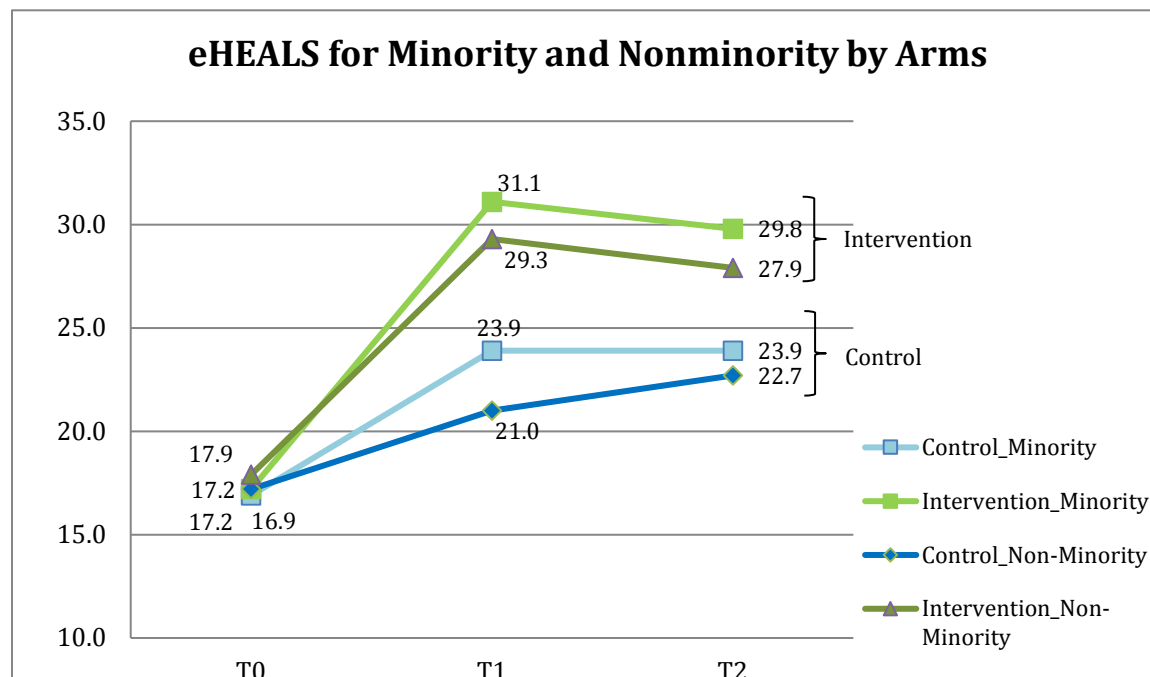


We conducted a similar analysis for eHealth literacy and observed similar although relatively larger effects. Participants in the lowest quartile ($n = 99$) showed the largest improvement from the intervention.

H 4.2: We will observe comparable improvements by race, ethnicity, and education.

We observed no statistically significant interactions by race/ethnicity or education for the interventions effects on tPAM, suggesting that similar effects were observed across these groups (Table 8); however, we did observe a statistically significant interaction in eHealth literacy for minority participants. Stratified analysis showed that minority participants showed greater improvements in eHealth literacy from the intervention than did nonminority participants (Figure 3). In a mixed model that adjusted for other characteristics, the *minority x intervention interaction* term was statistically significant ($P = .0275$).

Figure 3: eHealth Literacy Changes for Minority Versus Nonminority Group by Intervention



Adverse Events

There were no adverse events, serious or otherwise, that had any plausible relationship to the intervention.

DISCUSSION

In this randomized trial, we found that a multimodal patient self-management program for PLWH improved patient activation, eHealth literacy, and involvement in care.

Decisional Context

Clinicians and practices serving PLWH are confronted with the question: What can be done to improve patient activation and eHealth literacy among low-income PLWH? Our findings suggest that this multimodal intervention, which involves group training co-facilitated by patient peers, can accomplish this aim.

Study Results in Context

To our knowledge, this is the first randomized controlled trial of an intervention that was explicitly designed to improve patient activation among PLWH. McInnes et al. conducted a pre- post pilot (no control group) of a similar intervention among 14 low-income veterans living with HIV or HCV. Patient activation improved, but results were not statistically significant.⁵⁴

Our effects are potentially important. An observational study showed that a 5-point difference in PAM was associated with an 18% and 8% higher odds for ART adherence and viral suppression, respectively.⁵³ Among patients with PAM scores in the lowest quartile in our study, our intervention resulted in a nearly a 4-point adjusted increase in PAM compared with the control arm. Among participants with the lowest PAM scores (level 1), the intervention resulted in doubling of the odds ratio of moving up to the next level of activation. This increase from level 1 to 2 has been associated with a 30% reduction in the odds of having an ED visit.⁷² Similarly, patients with PAM level 1 are significantly more likely to develop a new chronic disease in the 3 years of observation, with odds ratios ranging from 1.21 to 1.31.⁷³

Other trials have assessed interventions for patients with other conditions—eg, diabetes, heart failure, hypertension, and in disease prevention.⁷⁴⁻⁸³ Our effects on PAM are larger than those from a randomized controlled trial of a Wellness Portal.⁷⁷ Results are similar to those observed from a randomized controlled trial involving low socioeconomic status patients being discharged from the hospital who were randomly assigned to trained community health workers or usual care,⁸⁴ but smaller than those from a heart failure self-management trial.⁷⁴ Our intervention appears to be unique in being explicitly designed by and for PLWH who are disproportionately poorer, less educated, and of minority status than the general population. It was designed to provide PLWH not only with knowledge and confidence in managing their health and health care but also with skills and tools (ie, a smart device) that enables self-management.

We did not observe statistically significant changes in HIV viral suppression or improvements in processes of care (ie, screening, immunization, and other preventive care). However, our study was not designed nor powered to examine viral load suppression, which is strongly linked to ART adherence. Nearly, three-quarters of participants had undetectable viral loads at baseline. We did not specifically focus on adherence skills and habits, which are strongly linked to viral load suppression.⁸⁵ Based on a modest relationship between PAM and adherence,⁵³ the improvements in PAM in this study were likely too small to show detectable effects on adherence or viral suppression.

Implementation of Study Results

Our intervention offers potential for implementation and scalability. The primary challenge is staff time to conduct training, and support for patients who cannot afford devices. However, many HIV practices, particularly those receiving Ryan-White HIV/AIDS funding, offer case management and group peer support programs.⁸⁶ Another option would be use of reimbursable group medical visits to conduct these trainings.⁸⁷

Our training manual provides a step-by-step, session-by-session approach for implementation. The key resources needed include staff and peer facilitators for groups, meeting space for groups, access to Wi-Fi (to minimize data use), and means to support

patients who don't currently own a smart device acquiring one. Despite persistent disparities by age and education in use of smart devices, national data show steady increases in such use, primarily for smartphones. Our experience is that a minority of patients lack access to these devices. In addition, we have developed a version of our ePHR that runs on Android devices, including Android phones. This new Android version will improve implementation by no longer requiring use of an iOS device (eg, iPod Touch or iPhone). We plan to use this device and offer a Spanish option if our PCORI dissemination and implementation funding is awarded.

Generalizability

Our patient inclusion criteria were very broad. Inclusion of community health centers probably enriched the participation of lower SES patients. We excluded very few participants. We excluded patients who participated in pilot versions of the program and a couple who lacked basic English language proficiency. We have addressed this limitation by developing a Spanish version of the intervention. Our practice criteria were also broad. All HIV practices in greater Rochester participated in addition to 4 large FQHCs in New York and New Jersey.

Subpopulation Considerations/Heterogeneity of Treatment Effects Analysis

Consistent with hypothesis 4.1, we observed that patients in the lowest quartile of activation showed the greatest improvement in activation. Some of this change might represent regression to mean. Notably, we observed comparable improvements by race, ethnicity, and education, with the exception of eHealth literacy, *where minority participants improved more with the intervention than did nonminority participants.*

Study Limitations

It is possible that patient activation training coupled with 1-time coaching prior to a single visit is insufficient to improve process of care. Our results in this respect contrast with those from a randomized controlled trial of an ePHR for patients with serious mental illness.⁸⁸ Differences may reflect the intervention design—eg, in that study patients were instructed to personally hand the clinician a printout of their PHR. Differences from that study also likely

reflect the large increase in the number of outpatient visits that the Druss et al. intervention had compared with the usual care arm (14.9 versus 0.5).⁸⁸

Ceiling effects hindered our ability to detect differences in suppressed viral load. More than 3 in 4 participants had viral suppression at baseline. Thus, we were significantly underpowered to detect changes in this secondary outcome.

Our design was pragmatic. We compared the intervention with usual care rather than with an attention control group; thus, we cannot exclude the possibility that groups per se improved patient activation. However, we are not aware that patient activation can be improved without addressing the core attitudes and skills that undergird this construct.

For disadvantaged patients, a 15-minute office visit is often insufficient time to address their concerns, provide evidence-based preventive care, engage in shared decision making, deliver relevant chronic care including support for patient self-management,⁸⁹ and address social determinants of health. About 5 minutes of each primary care visit are devoted to the patient's chief concern and a minute or less each to the remaining issues.⁹⁰ Most primary care visits address at least 3 concerns,⁹¹ but disadvantaged patients present with a greater number of concerns,⁹² many of which are related to the social determinants of health. Our clinician training emphasized helping patients to prioritize their concerns for the visit. For example, if the patient prioritized discussing back pain, a new rash, and life stress, then many of the questions prompted from the ePHR might not have been addressed. Thus, a single visit may not have been sufficient to address the combination of prompted issues and the patient's own primary concerns. Further, clinicians might not have universally ordered tests, immunizations, or cancer screening requested by the patient.

Further, it is conceivable that clinician training and cross-patient contamination sensitized clinicians to care processes among both treatment arms, thus biasing results toward the null. Last, while we documented continued use of the app by participants, it is possible that use was not sufficiently intensive to generate changes on more distal health outcomes.

Lack of blinding of participants and staff represents a potential threat to internal validity. Although participants were not aware of the specific study aims, participants receiving the intervention were aware of its focus—ie, training patients to be more activated. This

knowledge might have biased their responses to the various scales. Similarly, while we asked RAs not to ask participants which group they were assigned, we cannot be certain that participants did not provide this information, directly or indirectly. Thus, we cannot exclude the potential for lack of blinding of participants or staff to have biased the results.

There is a cost (roughly \$200) associated with purchase of an iPod Touch™, and people must carry this device along with their cellphone. We have recently addressed this challenge by developing a version of the app for Android phones. Suitable Android phones can now be purchased for \$60, to avoid use of 2 separate devices.

Use of smart devices can be a challenge for older persons with low vision. One participant mentioned that use of a stylus made key pressing easier; as result, we provided styluses to participants.

Future Research

The GREAT program was designed to promote patient activation and eHealth literacy to mitigate the impact of the digital divide on patient activation. Our trial results show that while we succeeded in enhancing patient activation, the primary outcome, those improvements were not associated with increases in medication adherence, reductions in HIV viral load, or increases in the delivery of preventive care. This project provides a foundation for next steps, including training modules that are more targeted toward ART adherence. Based on participants' feedback, there is strong patient desire for additional modules that address lifestyle concerns, including nutrition and physical activity, and use of apps that support them.

Nonetheless, there are significant barriers to using ePHRs to address health care disparities. Currently, only a handful of patients access these web-based ePHRs.³⁸ Moreover, while the disparities for minorities in online access continue to decline overall,⁹³ disparities in access to and use of web-based ePHRs persist. Specifically, blacks, Latinos, and those with low SES or those who are older use web-based ePHRs less frequently than do their counterparts.^{38,94-100} These disparities reflect the combination of lower health literacy combined with the so-called digital divide. Data from the US Census Bureau attest that poor, minority, and older patients use the web less often.¹⁰¹ National surveys (and our own preliminary data)

suggest that 3 factors largely contribute to the digital divide:³³ cost of web access, lack of interest, and lack of skills. In the absence of targeted mitigation strategies,¹⁰² access to web-based ePHRs will likely worsen rather than ameliorate health care disparities. One potential mitigating factor is that blacks and Latinos are more likely to use smartphones to access the web than are whites.³⁴ We created an Android version of the app to take advantage of this growing use of smartphones by minorities.

Conclusion

We confirmed our primary hypothesis—that this intervention would improve patient activation—but we did not observe improvements in adherence or recommended care. Findings from this study on activation add to the evidence on successful approaches that improve patient activation among patients with chronic conditions and address a notable gap in evidence regarding interventions for activating PLWH. The intervention effects seem to be greatest among those with lowest activation, suggesting potential targeting of this group.

The internal validity of these findings is strengthened by use of a randomized design, use of validated measures, intervention fidelity checks, good rates of participant retention, and very low rates of missing data; the primary threat to internal validity was inability to blind participants or research assistants.

External validity is strengthened by broad participant eligibility criteria, high rates of trial participation among potentially eligible patients, and use of trained peer facilitators. External validity is further strengthened by diversity among the practices that participated, including all 4 major HIV practices in Rochester and a diverse range of FQHCs in the New York City/northern New Jersey region.

The intervention was effective in improving patient activation, eHealth literacy, and involvement in care. These constructs are associated with important health outcomes, such as ED visits, avoidable hospitalizations, adherence, improved decision making, experience with care, and reduction in disparities.^{2,103-105} Nonetheless, the GREAT intervention did not show statistically significant improvements in self-reported ART adherence; viral load suppression; or uptake of evidence-based testing, immunizations, or preventive care. Future studies should

consider focusing activation interventions on nonadherent participants with detectable HIV virus.

Given these considerations, the GREAT intervention is likely to be of interest to practices and health plans concerned with improving patient activation. However, the absence of effects on adherence and update of evidence-care suggests that this intervention alone is not sufficient to appreciably improve these outcomes. Research should address targeted, possibly supplementary, approaches to adherence and uptake of evidence-based care for PLWH.

REFERENCES

1. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207-214.
2. Kinney RL, Lemon SC, Person SD, Pagoto SL, Saczynski JS. The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: A systematic review. *Patient Educ Couns*. 2015;98(5):545-552.
3. Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA*. 1999;282(6):583-589.
4. Saha S, Arbelaez JJ, Cooper LA. Patient-physician relationships and racial disparities in the quality of health care. *Am J Public Health*. 2003;93(10):1713-1719.
5. Mugavero MJ, Lin HY, Allison JJ, et al. Racial disparities in HIV virologic failure: do missed visits matter? *Journal of Acquired Immune Deficiency Syndromes: JAIDS*. 2009;50(1):100-108.
6. Gordon HS, Street RL, Jr., Sharf BF, Soucek J. Racial differences in doctors' information-giving and patients' participation. *Cancer*. 2006;107(6):1313-1320.
7. Street RL, Jr., Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care*. 2005;43(10):960-969.
8. Beach MC, Saha S, Korthuis PT, et al. Differences in patient-provider communication for Hispanic compared to non-Hispanic white patients in HIV care. *J Gen Intern Med*. 2010;25(7):682-687.
9. Hibbard JH, Greene J, Becker ER, et al. Racial/Ethnic Disparities And Consumer Activation In Health. *Health Aff (Millwood)*. 2008;27(5):1442-1453.
10. Heckman BD, Catz SL, Heckman TG, Miller JG, Kalichman SC. Adherence to antiretroviral therapy in rural persons living with HIV disease in the United States. *AIDS Care*. 2004;16(2):219-230.
11. Johnson MO, Chesney MA, Neillands TB, et al. Disparities in reported reasons for not initiating or stopping antiretroviral treatment among a diverse sample of persons living with HIV. *J Gen Intern Med*. 2009;24(2):247-251.

12. Fagerlin A, Sepucha KR, Couper MP, Levin CA, Singer E, Zikmund-Fisher BJ. Patients' knowledge about 9 common health conditions: the DECISIONS survey. *Med Decis Making*. 2010;30(5:Suppl):Suppl-52S.
13. Gourlay ML, Lewis CL, Preisser JS, Mitchell CM, Sloane PD. Perceptions of informed decision making about cancer screening in a diverse primary care population. *Fam Med*. 2010;42(6):421-427.
14. Crystal S, Sambamoorthi U, Moynihan PJ, McSpiritt E. Initiation and continuation of newer antiretroviral treatments among medicaid recipients with AIDS. *J Gen Intern Med*. 2001;16(12):850-859.
15. Pence BW, Ostermann J, Kumar V, Whetten K, Thielman N, Mugavero MJ. The influence of psychosocial characteristics and race/ethnicity on the use, duration, and success of antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndromes: JAIDS*. 2008;47(2):194-201.
16. Skarbinski J, Johnson C, Frazier E, Beer L, Valverde E, Heffelfinger J. Nationally Representative Estimates of the Number of HIV⁺ Adults who Received Medical Care, Were Prescribed ART, and Achieved Viral Suppression Medical Monitoring Project, 2009 to 2010 US. Paper presented at: 19th Conference on Retroviruses and Opportunistic Infections.
17. Yehia BR FJ, Metlay JP, Moore RD, Gebo KA. Sustained viral suppression in hiv-infected patients receiving antiretroviral therapy. *JAMA: The Journal of the American Medical Association*. 2012;308(4):339-342.
18. Hellinger FJ. The changing pattern of hospital care for persons living with HIV: 2000 through 2004. *Journal of Acquired Immune Deficiency Syndromes: JAIDS*. 2007;45(2):239-246.
19. Silverberg MJ, Leyden W, Quesenberry CP, Jr., Horberg MA. Race/ethnicity and risk of AIDS and death among HIV-infected patients with access to care. *J Gen Intern Med*. 2009;24(9):1065-1072.
20. French AL, Gawel SH, Hershow R, et al. Trends in mortality and causes of death among women with HIV in the United States: a 10-year study. *Journal of Acquired Immune Deficiency Syndromes: JAIDS*. 2009;51(4):399-406.
21. Puhan MA, Van Natta ML, Palella FJ, Addessi A, Meinert C, Group OCoAR. Excess mortality in patients with AIDS in the era of highly active antiretroviral therapy: temporal changes and risk factors. *Clin Infect Dis*. 2010;51(8):947-956.
22. Antiretroviral Therapy Cohort Collaboration, Zwahlen M, Harris R, et al. Mortality of HIV-infected patients starting potent antiretroviral therapy: comparison with the general population in nine industrialized countries. *Int J Epidemiol*. 2009;38(6):1624-1633.

23. Centers for Disease Control and Prevention. Deaths, percent of total deaths, and death rates for the 15 leading causes of death in 10-year age groups, by Hispanic origin, race for non-Hispanic population and sex: United States, 2014. 2017; http://www.cdc.gov/nchs/data/dvs/LCWK5_2008.pdf.
24. Tenforde M, Jain A, Hickner J. The value of personal health records for chronic disease management: what do we know? *Fam Med*. 2011;43(5):351-354.
25. Ko H, Turner T, Jones C, Hill C. Patient-held medical records for patients with chronic disease: a systematic review. *Quality & Safety in Health Care*. 2010;19(5):e41.
26. Crouch P-CB, Rose CD, Johnson M, Janson SL. A pilot study to evaluate the magnitude of association of the use of electronic personal health records with patient activation and empowerment in HIV-infected veterans. *PeerJ*. 2015;3:e852.
27. McInnes DK, Shimada SL, Midboe AM, et al. Patient Use of Electronic Prescription Refill and Secure Messaging and Its Association With Undetectable HIV Viral Load: A Retrospective Cohort Study. *J Med Internet Res*. 2017;19(2).
28. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation science : IS*. 2011;6:42.
29. Ancker JS, Osorio SN, Cheriff A, Cole CL, Silver M, Kaushal R. Patient activation and use of an electronic patient portal. *Informatics for Health and Social Care*. 2015;40(3):254-266.
30. Smith SG, Pandit A, Rush SR, Wolf MS, Simon CJ. The role of patient activation in preferences for shared decision making: results from a national survey of US adults. *Journal of health communication*. 2016;21(1):67-75.
31. Henselmans I, Heijmans M, Rademakers J, Dulmen S. Participation of chronic patients in medical consultations: patients' perceived efficacy, barriers and interest in support. *Health Expectations*. 2015;18(6):2375-2388.
32. Lyles C, Schillinger D, Sarkar U. Connecting the dots: health information technology expansion and health disparities. *PLoS Med*. 2015;12(7):e1001852.
33. Horrigan JB. *Broadband Adoption and Use in America*. OBI Working Paper Series No 1. Washington, D.C.: Federal Communications Division; 2011.
34. Anderson M. Digital divide persists even as lower-income Americans make gains in tech adoption. 2017; <http://www.pewresearch.org/fact-tank/2017/03/22/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/>.

35. Gidwani R, Zulman D. Association between acute medical exacerbations and consuming or producing web-based health information: analysis from Pew survey data. *J Med Internet Res*. 2015;17(6):e145.
36. Smith SG, Pandit A, Rush SR, Wolf MS, Simon C. The association between patient activation and accessing online health information: results from a national survey of US adults. *Health Expectations*. 2015;18(6):3262-3273.
37. Irizarry T, Dabbs AD, Curran CR. Patient portals and patient engagement: a state of the science review. *J Med Internet Res*. 2015;17(6).
38. Undern T. Consumers and Health Information Technology: A National Survey. 2010; <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/C/PDF%20ConsumersHealthInfoTechnologyNationalSurvey.pdf>.
39. Luque AE, Corales R, Fowler RJ, et al. Bridging the Digital Divide in HIV Care: A Pilot Study of an iPod Personal Health Record. *Journal of the International Association of Physicians in AIDS Care (JIAPAC)*. 2012.
40. Luque EA, van Keken A, Winters P, Keefer CM, Sanders M, Fiscella K. Barriers and Facilitators of Online Patient Portals to Personal Health Records Among Persons Living With HIV: Formative Research. *JMIR Res Protoc*. 2013;2(1):e8.
41. Committee PM, Helfand M, Berg A, Flum D, Gabriel S, Normand S, eds. *PCORI Methodology Standards* Washington, D.C.: Patient Centered Research Institute; December, 2012.
42. Boyle D, Dwinnell B, Platt F. Invite, listen, and summarize: a patient-centered communication technique. *Acad Med*. 2005;80(1):29-32.
43. Mauksch LB, Dugdale DC, Dodson S, Epstein R. Relationship, communication, and efficiency in the medical encounter: creating a clinical model from a literature review. *Arch Intern Med*. 2008;168(13):1387-1395.
44. Epstein RM, Mauksch L, Carroll J, Jaen CR. Have you really addressed your patient's concerns? *Fam Pract Manag*. 2008;15(3):35-40.
45. Brock DM, Mauksch LB, Witteborn S, Hummel J, Nagasawa P, Robins LS. Effectiveness of intensive physician training in upfront agenda setting. *J Gen Intern Med*. 2011;26(11):1317-1323.
46. Fiscella K, Meldrum S, Franks P, et al. Patient trust: is it related to patient-centered behavior of primary care physicians? *Med Care*. 2004;42(11):1049-1055.

47. Carroll JK, Fiscella K, Meldrum SC, et al. Clinician-patient communication about physical activity in an underserved population. *Journal of the American Board of Family Medicine: JABFM*. 2008;21(2):118-127.
48. Franks P, Jerant AF, Fiscella K, Shields CG, Tancredi DJ, Epstein RM. Studying physician effects on patient outcomes: physician interactional style and performance on quality of care indicators. *Soc Sci Med*. 2006;62(2):422-432.
49. Issenberg SB, McGaghie WC, Petrusa ER, Lee Gordon D, Scalese RJ. Features and uses of high-fidelity medical simulations that lead to effective learning: a BEME systematic review. *Med Teach*. 2005;27(1):10-28.
50. Cook DA, Hamstra SJ, Brydges R, et al. Comparative effectiveness of instructional design features in simulation-based education: systematic review and meta-analysis. *Med Teach*. 2013;35(1):e867-898.
51. Fiscella K, Franks P, Srinivasan M, Kravitz RL, Epstein R. Ratings of physician communication by real and standardized patients. *Ann Fam Med*. 2007;5(2):151-158.
52. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005;40(6:Pt 1):t-30.
53. Marshall R, Beach MC, Saha S, et al. Patient activation and improved outcomes in HIV-infected patients. *J Gen Intern Med*. 2013;28(5):668-674.
54. McInnes DKS, Solomon JLP, Shimada SLP, et al. Development and Evaluation of an Internet and Personal Health Record Training Program for Low-income Patients With HIV or Hepatitis C. *Med Care*. 2013;51 Health Information Technology in VHA Quality Improvement(Research):S62-S66.
55. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *J Med Internet Res*. 2006;8(4):e27.
56. Robinson C, Graham J. Perceived Internet health literacy of HIV-positive people through the provision of a computer and Internet health education intervention. *Health Information & Libraries Journal*. 2010;27(4):295-303.
57. Lerman CE, Brody DS, Caputo GC, Smith DG, Lazaro CG, Wolfson HG. Patients' Perceived Involvement in Care Scale: relationship to attitudes about illness and medical care. *J Gen Intern Med*. 1990;5(1):29-33.
58. Cranney A, O'Connor AM, Jacobsen MJ, et al. Development and pilot testing of a decision aid for postmenopausal women with osteoporosis. *Patient Educ Couns*. 2002;47(3):245-255.

59. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004;39(4 Pt 1):1005-1026.
60. Johnson MO, Neilands TB, Dilworth SE, Morin SF, Remien RH, Chesney MA. The role of self-efficacy in HIV treatment adherence: validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). *J Behav Med.* 2007;30(5):359-370.
61. Simoni JM, Kurth AE, Pearson CR, Pantalone DW, Merrill JO, Frick PA. Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. *AIDS Behav.* 2006;10(3):227-245.
62. Williams B, Diehr P, LoGerfo J. Evaluating a preventive services index to adjust for healthy behaviors in observational studies of older adults. *Prev Chronic Dis.* 2010;7(5):A110.
63. Gandek B, Ware JE, Aaronson NK, et al. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. *J Clin Epidemiol.* 1998;51(11):1171-1178.
64. Campbell C, Lockyer J, Laidlaw T, MacLeod H. Assessment of a matched-pair instrument to examine doctor–patient communication skills in practising doctors. *Med Educ.* 2007;41(2):123-129.
65. Patient-Centered Outcomes Research Institute. The PCORI methodology report. Available from: pcori.org/research-we-support/research-methodology-standards [Last accessed 20 March 2014]. 2013.
66. Little RJ, Rubin DB. *Statistical analysis with missing data*. John Wiley & Sons; 2014.
67. Donner A, Klar N. Statistical considerations in the design and analysis of community intervention trials. *J Clin Epidemiol.* 1996;49(4):435-439.
68. Thompson DM, Fernald DH, Mold JW. Intraclass correlation coefficients typical of cluster-randomized studies: estimates from the Robert Wood Johnson Prescription for Health projects. *Ann Fam Med.* 2012;10(3):235-240.
69. Hintze J, LLC N. *PASS 11* Kaysville, Utah, USA2011.
70. Zhao W. Paper 336-2012; A Generalized Approach to Estimating Sample Sizes SAS Global Forum 2012; April, 2012, 2012; Orlando, Florida.
71. Rubin DB. Multiple imputation after 18+ years. *Journal of the American statistical Association.* 1996;91(434):473-489.

72. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. *Health Aff (Millwood)*. 2015;34(3):431-437.
73. Hibbard JH, Greene J, Sacks RM, Overton V, Parrotta C. Improving Population Health Management Strategies: Identifying Patients Who Are More Likely to Be Users of Avoidable Costly Care and Those More Likely to Develop a New Chronic Disease. *Health Serv Res*. 2017;52(4):1297-1309.
74. Shively MJ, Gardetto NJ, Kodiath MF, et al. Effect of patient activation on self-management in patients with heart failure. *J Cardiovasc Nurs*. 2013;28(1):20-34.
75. Frias J, Viridi NS, Raja P, et al. Evaluation of a Digital Health Offering to Optimize Blood Pressure and Lipid Control in Patients With Uncontrolled Hypertension and Type 2 Diabetes: A Pilot, Cluster Randomized Study. In: Am Heart Assoc; 2016.
76. Wagner PJ, Dias J, Howard S, et al. Personal health records and hypertension control: a randomized trial. *J Am Med Inform Assoc*. 2012.
77. Nagykaldi Z, Aspy CB, Chou A, Mold JW. Impact of a Wellness Portal on the delivery of patient-centered preventive care. *Journal of the American Board of Family Medicine: JABFM*. 2012;25(2):158-167.
78. Wolever R, Dreusicke M, Fikkan J, et al. Integrative health coaching for patients with type 2 diabetes a randomized clinical trial. *The Diabetes Educator*. 2010;36(4):629-639.
79. Lorig K, Ritter PL, Laurent DD, et al. Online diabetes self-management program. *Diabetes Care*. 2010;33(6):1275-1281.
80. Lorig K, Ritter PL, Villa FJ, Armas J. Community-based peer-led diabetes self-management a randomized trial. *The Diabetes Educator*. 2009;35(4):641-651.
81. Deen D, Lu WH, Weintraub MR, Maranda MJ, Elshafey S, Gold MR. The impact of different modalities for activating patients in a community health center setting. *Patient Educ Couns*. 2012;89(1):178-183.
82. Rygg LØ, Rise MB, Grønning K, Steinsbekk A. Efficacy of ongoing group based diabetes self-management education for patients with type 2 diabetes mellitus. A randomised controlled trial. *Patient Educ Couns*. 2012;86(1):98-105.
83. Maindal HT, Sandbæk A, Kirkevold M, Lauritzen T. Effect on motivation, perceived competence, and activation after participation in the “Ready to Act” programme for people with screen-detected dysglycaemia: a 1-year randomised controlled trial, Addition-DK. *Scand J Soc Med*. 2011;39(3):262-271.

84. Kangovi S, Mitra N, Grande D, et al. Patient-centered community health worker intervention to improve posthospital outcomes: a randomized clinical trial. *JAMA internal medicine*. 2014;174(4):535-543.
85. Cohen SM, Hu X, Sweeney P, Johnson AS, Hall HI. HIV viral suppression among persons with varying levels of engagement in HIV medical care, 19 US jurisdictions. *J Acquir Immune Defic Syndr*. 2014;67(5):519-527.
86. Weiser J, Beer L, Frazier EL, et al. Service delivery and patient outcomes in Ryan White HIV/AIDS Program–funded and–nonfunded health care facilities in the United States. *JAMA internal medicine*. 2015;175(10):1650-1659.
87. Quiñones AR, Richardson J, Freeman M, et al. Educational group visits for the management of chronic health conditions: a systematic review. *Patient Educ Couns*. 2014;95(1):3-29.
88. Druss BG, von Esenwein SA, Compton MT, Rask KJ, Zhao L, Parker RM. A randomized trial of medical care management for community mental health settings: the Primary Care Access, Referral, and Evaluation (PCARE) study. *Am J Psychiatry*. 2010;167(2):151-159.
89. Fiscella K, Epstein RM. So much to do, so little time: care for the socially disadvantaged and 15-minute visits. *Arch Intern Med*. 2008;168(17):1843-1852.
90. Tai-Seale M, McGuire TG, Zhang W. Time allocation in primary care office visits. *Health Serv Res*. 2007;42(5):1871-1894.
91. Beasley JW, Hankey TH, Erickson R, et al. How many problems do family physicians manage at each encounter? A WReN study. *Ann Fam Med*. 2004;2(5):405-410.
92. Mauksch LB, Katon WJ, Russo J, Tucker SM, Walker E, Cameron J. The content of a low-income, uninsured primary care population: including the patient agenda. *J Am Board Fam Pract*. 2003;16(4):278-289.
93. Smith A. *U.S. Smartphone use in 2015*. Washington, D.C.2015.
94. Yamin CK, Emani S, Williams DH, et al. The digital divide in adoption and use of a personal health record. *ArchInternMed*. 2011;171(6):568-574.
95. Sarkar U, Karter AJ, Liu JY, et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *J Am MedInformAssoc*. 2011;18(3):318-321.
96. Byczkowski TL, Munafo JK, Britto MT. Variation in use of Internet-based patient portals by parents of children with chronic disease. *ArchPediatrAdolescMed*. 2011;165(5):405-411.

97. McInnes DK, Gifford AL, Kazis LE, Wagner TH. Disparities in health-related internet use by US veterans: results from a national survey. *InformPrimCare*. 2010;18(1):59-68.
98. Roblin DW, Houston TK, Allison JJ, Joski PJ, Becker ER. Disparities in use of a personal health record in a managed care organization. *J Am MedInformAssoc*. 2009;16(5):683-689.
99. Goel M, Brown T, Williams A, Hasnain-Wynia R, Thompson J, Baker D. Disparities in Enrollment and Use of an Electronic Patient Portal. *J Gen Intern Med*. 2011;26(10):1112-1116.
100. Ancker J, Barr+¹n Y, Rockoff M, et al. Use of an Electronic Patient Portal Among Disadvantaged Populations. *J Gen Intern Med*. 2011;26(10):1117-1123.
101. United States Census. *Reported internet usage for households by selected householder characteristics, 2009, Table 1*. 2011 2011.
102. Hilton JF, Barkoff L, Chang O, et al. A cross-sectional study of barriers to personal health record use among patients attending a safety-net clinic. *PLoS ONE [Electronic Resource]*. 2012;7(2):e31888.
103. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ open*. 2013;3(1):e001570.
104. Durand M-A, Carpenter L, Dolan H, et al. Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PLoS One*. 2014;9(4):e94670.
105. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. *J Med Internet Res*. 2013;15(5):e93.

G.R.E.A.T. Training Manual

2014



Principal Investigator: Kevin Fiscella, MD
MPH

Version 5: June 2014

Table of Contents

Overview of Intervention	4
Principles for Conducting Sessions.....	4
General Structure of Session	5
Classroom Climate.....	6
Learning Objectives	6
Syllabus	6
How to use this manual	7
Guidelines for Success	7
Lesson 1: Introduction: Becoming an Active patient and iPod Basics	8
Welcome and Classroom rules	9
Why it is important to be an active patient.....	10
BASIC operating features	10
Password to lock the device.....	11
Calendar.....	12
Contacts	12
Notes	13
Recap.....	14
Lesson 2: iPod basics and Finding reliable health information).....	15
Re-cap prior lesson and answer questions	15
Safari tutorial	16
Email documents	18
Installing App	19
Review	19
Lesson 3: Introduction to (ePHR)	20
Re-cap last week's lesson and/or answer questions	20
Personalizing the app.....	21
Personalized and enter Emergency Contacts	22
Input Allergies, Medication, Tests and Procedures	22
Back-up Data/Restore	23
Review materials	23
Lesson 4: HIV Basics and Keeping Track	24
Re-cap prior lesson and/or answer questions	24
HIV virus, CD4 cells and HIV tests	25
HIV medication actions	25
Entering tests and medications into PHR	26
Look at trends (personal cell counts, etc.) using graphs	26
Review	27

Lesson 5: Asking questions that <u>you</u> want to ask	28
Re-cap last week's lesson/answer questions	28
Why your questions matter	29
Reason patients don't ask question	29
Types of questions: Closed vs. Open	29
Role Play	30
Group Share	31
Wrap-up	32
Lesson 6: APPS and Wrap-up	33
Recap.....	33
AIDSinfo Glossary and iTunes/App Store	34
Practice using MyFitness Pal	35
Practice using other Apps	35
Recap of training	36
Certificates	36
Individual Coaching Session: Putting it into action.....	37
Before the coaching session	37
During the coaching session	38
Participant Commitment Form	39
<u>WHERE IS IT?</u> Hand-out	40
Websites, Apps Hand-out.....	41
Email Protection Tips.....	42
<u>ASKING QUESTIONS</u> Hand-out	44
Communication Tips: Individual Coaching Session Hand-out	45
Role Play Scenarios	47

OVERVIEW OF INTERVENTION

This program is designed to address disparities in HIV care by empowering patients (giving them a voice). The program includes the provision of a hand held device (iPod Touch™) and an electronic Personal Health Record (ePHR) application () coupled training. Participants are trained to: 1) use of the device and the PHR, 2) acquire the attitude, confidence and skills to be activated patients.

Patient activation involves recognition of **Why** it is important for patients to assume a greater role in their care, acquiring the **Know How**, i.e., the knowledge and confidence to take action including **communicating with one's doctor**; and ability to **Take Action** including adopting a **healthy lifestyle** and **problem solving**.

Principles for Conducting Sessions

The sessions are based on adult learning principles.¹ These include:

Adults are internally motivated and self-directed. We design our sessions to optimize internal motivation by supporting patient autonomy (self-direction and hands on), competence (instruction followed by immediate practice and demonstration), and relatedness (encouraging shared learning and celebrating success).² We begin with participants experience and use that as a basis for skills development. We use co-learning, peer-teaching, and extra help sessions to account for variation in experience and ability. We encourage active exploration (and subsequent sharing of experience) of suggested Web-sites outside of training sessions, (e.g., MedlinePlus, TheBody.Com) and suggest health related applications. Last, we assign practical homework assignments. Sessions are learner-focused rather than instructor driven.

Adults bring broad life experiences and knowledge to learning experiences. While many participants lack familiarity with computer devices and PHRs, all have experiences with health care and decisions. We use participants' own real life experiences and dilemmas, i.e., their strengths, as the basis for training by inviting participants to share their experiences and including effective strategies for common problems relevant to each session.

Adults are goal oriented. Each session is focused on achieving specific objectives. Participants are encouraged to share learnings and skills with the group or with a partner in the group as a means for demonstrating they have achieved the goal of each session.

Adults are relevancy oriented. The training is directly linked to patients own HIV care. We train participants how to think about questions and concerns that are most relevant to them.

Adults are practical. We encourage participants to share their own experiences in applying what they learned to real life practical problems. Our teaching is solution

focused rather than dwelling on painful traumatic experiences with the health care system.

Adult learners want to be respected. We recognize regardless of skill level every participant has something important to contribute including their own life experience related to having a voice in HIV care. Each session is designed to ensure every voice is heard and respected.

General Structure of Session

- 1) The instructor follows up on homework assignments and invites participants to demonstrate skills to partner and vice versa and celebrate participant “new successes.”
- 2) Instructor introduces new topic, explains its relevance to health care, and invites participants to briefly share their experiences.
- 3) Instructor demonstrates skill using iPad or verbally (for communication skills) while inviting participants to follow along.
- 4) Participants pair-up and demonstrate to partner (only ask for assistance after trying for 5 minutes on own).
- 5) Brief sharing of learnings with group and on to next topic.

CLASSROOM CLIMATE

- 1) Create a climate that is safe, participatory, focused on learning new information and skills - and most importantly – fun.
- 2) Promotes successful solutions based on participants sharing.
- 3) Respectful atmosphere where all voices are acknowledged.
- 4) Make sure that everyone is keeping up and engaged.

LEARNING OBJECTIVES

- 1) To know what an active patient means.
- 2) To know why it is important to become an active patient.
- 3) To acquire skills in basics of iPod operation.
- 4) To know HIV basics including the meaning of key tests and medications.
- 5) To acquire skills in basics of the ePHR.
- 6) To acquire skills in developing and asking the right question.
- 7) To acquire skills in obtaining reliable health information.
- 8) To acquire skills in using applications that supports a healthy lifestyle.

SYLLABUS

Lesson 1: Introduction: Becoming an Active patient and iPod Basics

Lesson 2: iPod basics and Finding reliable health information

Lesson 3: Introduction to (ePHR)

Lesson 4: HIV Basics and Keeping Track

Lesson 5: Asking questions that you want to ask

Lesson 6: Apps and Wrap-up

Individual Coaching Session: Putting it into action

How to Use this Manual

Guidelines for Success

The G.R.E.A.T. iPod training program is an intervention aimed at increasing patient communication with their doctor. It includes a series of exercises to help familiarize patients with the iPod device, utilize various Apps, and facilitate patient question asking when interacting with their doctor.

Suggested script will be boxed, bolded, and italicized as follows:

These sentences provide examples for Trainers to present topics or exercises to participants. They can be paraphrased or delivered as written.

The six training sessions and individual coaching session have specific tasks and suggested time frames for each section. However, do not let the pressure of having to go through every section stop the natural flow of the class or harm rapport building with the class.

Each Trainer has her/his own personal style. Following a manualized intervention does not mean that you cannot blend that style into your interaction with the class. Being warm, attentive, and a good listener will help the class learn the skills and buy into each lesson. **Your enthusiasm will be contagious!**

As the classes progresses and participants feel more comfortable, they may begin to reveal very personal information with the Trainer and/or the group. However, you should never think of yourself as a doctor or therapist. The same goes for other participants in the group as well, because they too will offer (at times unwarranted) feedback. It is **crucial** that you clarify the purpose of the class, and emphasize **Trainers are not qualified to answer their medical questions or provide feedback** on their opinions about their doctor or health center. Getting into those types of information sharing with participants can undermine the work being done in the group and breakdown trust. The goal is to help participants bring these questions/thoughts back to their doctor as new questions.

Lesson 1: Introduction: Becoming an Active patient and iPod Basics

Learning Objectives for Session #1

1. To show **why** it is important for patients to become more active and engaged in their health care, i.e., to become active patients.
2. To provide a brief overview of how the iPod can help participants become more active patients.
3. To acquire skills in basic iPod functions (see specific tasks below).

For many participants, this will be the first time they have ever had contact with an iPod, smart device, or computer. The goal of the first session is to increase comfort with powering on/off the device and using basic functions on the device. This will be an important class to have assistant trainers help the trainer. Their primary role will be to walk around and make sure everyone is on track. This class will also help gauge the pace in which the remaining classes will go, because it will give the trainer an idea of where each participant stands in terms of comfort with the device. This is also an important class to make participants feel confident using the device and not feel overwhelmed with what is being taught, so they will want to come back. REMEMBER to go slow and to encourage the participants to stop you and ask a lot of questions.

Activities

- A. Welcome and Classroom rules (5 minutes)
- B. Why it is important to be an active patient (15 minutes)
- C. BASIC operating features (10 minutes)
- D. Password to lock the device (10 minutes)
- E. Calendar (15 minutes)
- F. Contacts (15 minutes)
- G. Notes (10 minutes)
- H. Recap (10 minutes)

A. WELCOME and CLASSROOM RULES (5 minutes)

It is very nice to meet all of you. My name is _____ and I will be your Trainer for these classes. We will have a total of 6 trainings together as a group, and then an additional one on one meeting one month after the training is complete. I am not a doctor, so I am not able to answer questions about your HIV care. I do hope to be a good trainer for you as you learn to use your iPod.

The goal of these trainings is to help everyone here become more active in their own care. These sessions will give you the tools and knowledge to do that. This will mean going home and practicing what you learn here. It also helps when you teach others. There is no better way to learn how to do something than to teach it to someone else.

Over the next few sessions we will share with you some tools you can use on your iPod to help better manage your care, as well as help you to come up with questions to ask your doctor. With some work and lots of practice, we expect that you will soon become GREAT at managing your care. Any questions so far?

Before we go any further, we want you to be certain and reaffirm that you are able and willing to commit to this study and these trainings. We are asking that you read this form. (Pass out the Participant Commitment Form) If you want me to, I will read it out loud and you follow along. If you find that you are still ready to commit, please sign and date the form.

*Use the Participant Commitment Form

Take a few minutes to review “classroom etiquette”. This includes raising their hands when they have something to share, volume (inside voices), and respecting each other’s comments/questions. Also take time to review the policy on lost/stolen devices, missing classes, and coming in for extra help (see study protocol). Confidentiality cannot be stressed enough. Reassure the participants that their private health information will be kept with the strictest confidence. As a trainer, you do not want the participants to get into the habit of sharing too much personal information because that is not the purpose of the training. However, occasionally it does happen and they need to feel comfortable that their information is safe.

It is important that everyone understand that what we talk about in class is private, and who we see in class is private. We all signed a confidentiality agreement during the consenting process saying we were not going to share what happens in class with anyone else, and we are all being held to that. This includes sharing who you see here and what they say with your doctor, social worker, psychiatrist, therapist, mother, father, etc.

Any questions?

B. WHY IT IS IMPORTANT TO BE AN ACTIVE PATIENT (15 minutes)

Next, introduce the concept of “an active patient”, why it is important and how the iPod can help.

*Let's begin by talking about the difference between patients who are not involved in their care (**"Just tell me what to do, doc"**) and **active patients** who take active role in their health care, becoming full partners with their doctor. Can you give me examples of non-active patients? Active ones?*

Which kind of patient do you want to be? Why?

Can you give me examples of how being an active patient helps you stay healthy?

What does it take to become an active patient?

The iPod can help you become a more active patient. Let me show you how it works

C. BASIC OPERATING FEATURES (10 minutes)



This will be the first time that many of the participants will have touched an iPod so you will need to go slow to make sure they are comfortable with the device. Give each participant their iPod and have them take them out of the case. Show them where the power on button is, have them power the device on. Next show them where the charger/cord connects to the iPod. Give each participant a USB charger, and have them practice plugging them into the power outlet and computer. The idea that the iPod can be charged by both the computer and the wall outlet is a new concept for some. Remind them that the computer needs to be powered on in order for the iPod to charge.

To make the class flow smoothly, it is important that everyone speak the same “iPod language”. Give each participant a large printout of the iPod picture. Use your iPad to point out where each of the features/buttons is located. Some of the participants may already know what these features are. Feel free to have them demonstrate/teach the class where they are and for what they are used.

**“WHERE
IS IT?”
hand-out**

Before we start using our iPod, it is important that we all understand some basic vocabulary I will use throughout the training. The first one we will learn this week is HOME. HOME can be our best friend when we are lost. It will get us back to our starting point if we get lost. The home button is located here (point it out). Everyone practice pushing your HOME button. (Let them push the button 2-3 times)

Good.

The next word, “APP”, is short for application. It is a shortcut to programs that are downloaded on your device. Such as__ (point out one of the pre-loaded apps). Can any one name any other apps that you see are already downloaded on your iPod?

Great!

Again, some of the participants may already know some of the answers so give them opportunity to share what they already know with the class. After you present each feature (using the picture as a guide), give them an opportunity to comment, ask questions, and practice doing it on their own iPods.

D. PASSWORD TO LOCK THE DEVICE (10 minutes)

You will go into SETTINGS and demonstrate to the participants how to set-up a password to lock their device. This is important because they will be storing personal information about their health on the device. The password offers a way for them to feel a bit more comfortable with the idea. If the device is ever lost or stolen, the password offers an extra layer of protection. It may also prevent thieves from taking the device if they know they need a password. Again, invite the participants to share any thoughts/concerns they may have. Before they set the password, remind them there is **NO WAY TO RETRIEVE IT ONCE IT IS SET WITHOUT WIPING OUT EVERYTHING THEY HAVE STORED SO FAR ON THE iPod SO WRITE IT DOWN OR MAKE SURE IT IS SOMETHING THEY ARE SURE THEY WILL NOT FORGET!**

The first thing we are going to learn to do is set our passwords to get into the iPod. Can anyone think of any reasons why the passwords would be necessary?

Good.

Before I show you how to set your password, I need you to think of a 4 digit password you will not forget. If you forget your password, we will have to "wipe" your iPod. That means we will have to delete everything that is stored on it so far and start from scratch. You should probably write it down for now, so that you will have it handy.

Go ahead and choose a password, write it down, and I will demonstrate how to set

participants
want for
ess.

E. CALENDAR (15 minutes)

The participants can use the calendar to store upcoming appointments, set medication reminders, birthdays, etc. This will likely be a feature that they use a lot. Remind them the calendar does **NOT HAVE A PASSCODE**, so if they let someone use their iPod and they look at their calendar they can see what they have put in their calendar. So it is important to be mindful of how much detail you include on the calendar.

Can anyone think of what the calendar maybe useful for? (Invite all to share)

Fantastic!

Now, let's practice putting in a few appointments. We can begin by putting in the rest of the classes for this training. I will show you how to enter an

You should list the dates for the upcoming classes on the board. If they are not able to enter them all into the iPod during the time you have allotted. They can write them down, and input the rest for homework. **THIS MAY TAKE LONGER THAN EXPECTED.** This is the first time that some of them have had to operate a digital keyboard or any keyboard at all! It can take some getting used to, even if you are an experienced typist.

F. CONTACTS (15 minutes)

The participants can use the contacts to store phone numbers for their doctors, pharmacists, emergency contacts, friends, family, etc. It is a convenient way for them to store it all in one place without flipping through papers and trying to commit phone numbers to memory.

Can anyone think of what the contacts maybe useful for? (Invite all to share)

You all are great!

Now, let's practice putting in a few contacts. We can begin by putting in my information in case you need to contact me between classes. I will show you how to enter it in on my iPad and then have you practice doing it on your iPod.

ain, have

G. NOTES (10 minutes)

The participants can use the NOTES to store questions they want to ask during their next visit. However, this is not password protected. They need to be mindful of how much PHI the store here. The NOTES can also be useful for things like grocery list, quick thoughts, etc.

Can anyone think of what notes may be useful for? (Invite all to share)

Fantastic!

We are going to learn how to use NOTES application, which is already installed in the device. Press NOTES on your home screen. Why is this useful?

have

Good. When you don't have a pen or paper, you could easily write the information on the iPod. You could even write questions you want to ask your doctors and bring those in. Also, you could also export notes to your email.

The title of the notes is going to be whatever you put on the top of the list. We are going to practice this by making a to-do list. So, at the very top, write "To-Do List." You can see that it automatically becomes a title. Press return to go to the next line and type "go for a walk". You could also write horizontally with a larger keyboard by turning the device.

If you want to create a new note, what do you press? (Plus sign!) Good job. So, there are four buttons on the bottom. The buttons on the very left and very right

H. Recap (10 minutes)

Take the time to review everything that they learned today. This information should come from them.

Let's review what we went over today, who can tell us one thing we learned? And why it is important?

Excellent!

Any questions?

For homework, remember to practice entering in your notes, contacts, and write down any questions you have during the week. Also, start getting your test results, immunizations and medication lists for use in the third class.

Lesson 2: iPod basics and Finding reliable health information

The goal of this lesson is for participants to learn how to obtain accurate information about their health including HIV on the Web.

Learning objectives

1. To learn about email
2. To learn about the World Wide Web
3. To learn how to search for accurate health information
4. To identify reliable websites and book mark them
5. To practice generating questions and searching for answers.
6. To understand different types of questions

Activities

- A. Re-cap prior lesson and answer questions(10 min)
- B. Safari tutorial (40 min)
- C. Email documents (20 min)
- D. Installing App (10 min)
- E. Review (10 min)

A. RE-CAP PRIOR LESSON AND ANSWER QUESTIONS (10 MIN)

It is important that you go over the material that they learned from last week to refresh their memories and get them to feel comfortable using the devices again (in case they haven't been using the iPods). It is also a good idea to encourage them to ask questions about things they can't figure out on their own. Share their questions with the class and encourage others to answer if they know. Make sure there is no confusion or frustration at the beginning of the class. This will make the participants feel more comfortable learning new things.

Before we start our new lesson, let's review what we learned last week. Does anyone know how to turn on the iPod? Put in password to enter your iPod? What happens if we forget our passwords to unlock our iPods? (Let them answer)

Good.

Now, did you all finish your homework? Was everyone able to write notes, log appointments into your calendar and add contacts?

Good.

Is there any question that you came across while doing your homework? (Give them time to ask questions)

B. SAFARI TUTORIAL (40 MIN)

Take a few moments to describe what Wi-Fi is, and how to access it. Remind participants they will need access to Wi-Fi to use the internet and download Apps. Go over where some FREE local Wi-Fi and hot spots are (McDonalds, Starbucks, etc.). Some other vocabulary words you will need to review are: web address, address bar, internet, Google, Safari, Chrome and search engine.

Now that we have some basic vocabulary down, let's practice going to some helpful websites.

Before we begin, anyone have any helpful health focused websites they would like to share with the group? We can preview those briefly as well.

Demonstrate how to navigate using Search Engine. Distinguish the difference between a search engine bar and just an address bar. They seem to be really confused between these two with Safari.

Demonstrate that they could turn their screen horizontally to enlarge the screen. Also, explain all the little buttons on the bottom – return to previous page, go back to the next page, exporting to different locations, and book marking.

**Websites,
APPs
Hand-out**

Now, we are going to navigate further into how to use the Internet. The Internet in an Apple Product is called "Safari". So, what is the Internet?

Yes, that's correct. The Internet or Safari is only accessible when there is any Wi-Fi connection available around you. There are many "hot spots" where you could find free Wi-Fi. What are hot spots?

That is correct. First you will touch the Safari icon on the screen. You will see two bars on the top, one is an address bar and another is a search bar. The address bar is where you type in an actual address for the Internet (www.aidsinfo.nih.gov) and the search bar is when you want to type in whatever you are looking for (AIDSinfo). Most of the times, you want to use the search engine bar unless you know the accurate address.

There are going to be several buttons on the bottom of the screen that is not going to change no matter where you navigate to. The arrow that faces left is a back button; the other is a forward button. The export button allows you to add the page to bookmark, reading list, home screen, and mail link to this page. The bookmark function could be extremely useful when you are trying to save pages so you could read later. It will allow you to access pages without typing everything again and trying to search the page. Your bookmarks could be accessed by pressing the book icon right next to it. The last button shows how many pages you have. If you press it either you could close pages or create new page. You could only have 8 pages as maximum.

So, how is Safari beneficial in our lives? How is Google Chrome different? How could this benefit our health?

True. Some of the important sites that could really help are Medline Plus and AIDSinfo. So, go to the search engine and type AIDSinfo and access the first website. This will allow you to view the iPhone friendly site, and it does look different from a regular full site. However, most of the information is in the concise website.

GO
SLOW



Show them some of the useful Health Sites such as MedlinePlus and AIDSinfo. This will give them practice on how to navigate and surf the Internet. Also, teach them the difference between a full site and a smart phone friendly site. They seem to be really confused that iPods and iPads have two different screens at first. The last thing you want to point out on the sites is that they have Apps that they can download.

C. EMAIL DOCUMENTS: DEMONSTRATE USING THE IPAD (20 MIN)

Email Protection – hand-out sheet will be given out. Make participants aware that once the email is connected to the device, anybody could access it.

*Use the
Email
Protection
Tips Sheet

Explain to them the concept of email and let them discuss what is safe and what is not. **Have participants brainstorm/share how it may be useful to them.** You can prompt the conversation by mentioning one of the following ideas: (sending it to the wrong person by accident, it becomes permanent). Ways to get around it? **Have participants brainstorm/share how it may be useful to them.** You can prompt the conversation by mentioning one of the following ideas: Using different email addresses for different things, multiple passwords, and etc.

Email can be a very useful tool. Some of you had an email address when you signed up for this program. What do you use it for? What are the benefits?

Those are all great ideas. We must also talk about the dangers of using email. Can anyone think of any?

Good.

So today I will show you how to use access your email accounts.

Teach them how to connect their iPod to the email. Go to SETTINGS -> MAIL, CONTACTS, and CALENDARS. Add account using the email that all of them should have (password is required). After, they will be able to access their email by using the "MAIL" application on the home screen.

The goal of this part of the training was just to show you that you have the ability to email, not necessarily to teach you how to do it. That can be very complicated, and we don't have that kind of time to spend during this class to get into it too deep. However, if you would like to learn more feel free to come to an extra help session and we can work one on one with you.

Any questions?

Great!

D. Installing App (10 MIN)

You should send the patients the link to download the "" app ahead of time. Ask them to go to the email and click on the link provided and then download the app on to their iPods. This will most likely be the first application they download and install, so make sure to give them plenty of time to try it on their own. This will help them become comfortable with trying to download more apps in the future. Have your assistants walk around and assist them as needed.

Now we are going to install the app on your iPods. You all should have received an email from me with a link.

(Demonstrate this on your iPad)

Follow along with me. Everyone tap your email button located at the bottom of your iPod, this icon here. Now that it is open, tap on the email you have from me, and you should see what we call a link. It looks like this. Tap on the link. Is everyone with me?

Good

Now, tap on the install button and wait a few moments. In a minute or so your app should be begin to download onto your iPod. Anyone need help?

Great job! Now all you have to do is to wait for the app to be downloaded.

We will work further with this app next week.

E. Review (10 MIN)

Let's review what we went over today, who can tell us one thing we learned? And why it is important?

Excellent!

We went through a lot of new things today. Any questions?

For homework, further explore some of the websites we visited today and see if you can identify a few new ones on your own. I am sure many of you will discover

Lesson 3: Introduction to (ePHR)

Learning Objectives for Session #3

1. To learn how a PHR can be helpful in becoming a more active patient.
2. To learn how to personalize and protect information in
3. To learn how to navigate it
3. To learn how to input data

By this week, the participants should be familiar with their iPods. This third session will introduce them to the “UR Health” app. This will also be an important class to have assistant trainers help the trainer since manipulating the app can take some time to get used to for the patients. The assistants’ primary role will be to walk around and make sure everyone is on track. This is also an important class to make participants feel the practical benefits that the iPods can contribute to their health. REMEMBER to go slow and to encourage the participants to stop you and ask a lot of questions.

Activities

- a. Re-cap last week’s lesson and/or answer questions (10 minutes)
- b. Personalizing the App (10 minutes)
- c. Personalized and enter Emergency Contacts (20 minutes)
- d. Input Allergies, Medication, Tests and Procedures (30 minutes)
- e. Back-up Data/Restore (5 minutes)
- f. Review materials (15 minutes)

A. Re-cap last week lesson and/or answer questions (10 minutes)

It is important that you go over the material that they learned from last week to refresh their memories and get them to feel comfortable using the devices again (in case they haven’t been using the iPods). It is also a good idea to encourage them to ask questions about things that they can’t figure out on their own. Share their questions with the class and encourage others to answer if they know. Make sure that there is no confusion or frustration at the beginning of the class this will make the participants feel more comfortable learning new things.

Before we start our new lesson, let’s review what we learned last week. What is the internet on your iPod? What do you need to access to use the internet, check your email, and download apps? (Let them answer)

Excellent!

Now, did you finish your homework? Did you discover any new websites?

Good!

Are there any questions about your homework or what we covered so far? (Give them time to ask questions)

Great!

B. PERSONALIZING THE APP (10 MINUTES)

You should explain to them that the purpose of is to keep track of their health records and appointments and to keep their information handy.

Last week, we installed the app on our iPods. Remember we talked about how these trainings would provide tools you can use to help you better keep track of your healthcare?

Well, this app is developed to help you keep track of appointments and medications. Now you will learn how to use it. Just like the last class, I will show you step by step on my iPad, and then you can practice on your own.

The first thing they will need to do is to set a password for the app. This is important because they will be storing personal information about their health in this app. In case they let other people use their iPods, they can still keep this information private. Before they set their password, remind them that this 4 digit code is different than the one they use to unlock their iPods. They can recover this password using the password recovery system. It will send their password to their email address. STILL, LET THEM KNOW TO WRITE IT DOWN OR TO MAKE SURE THAT IT IS SOMETHING THEY WILL NOT FORGET.

The first thing we are going to learn to do is set our passwords to get into the app. Can anyone think of a reason why the password would be necessary?

Good.

Before I show you how to set your passwords, like last time, I need you to think of a 4 digit password you will not forget. If you forget your password, you can get it sent to your email. This password should be different than the one you use for your iPod. So you should probably write it down for now, so that you will have it

The application should automatically ask you to enter the password before you enter. You can change this code by going to PROFILES and hit "Change PIN". Show the participants how to do this also. Let them do it on their own while having the assistant trainers walk around and help them through the process.

C. PERSONALIZE AND ENTER EMERGENCY CONTACTS (20 MINUTES)

The participants can go to the PROFILE page and enter EMERGENCY CONTACT information. This information will show up when someone clicks on their App, even without the person having to enter the passcode. This can be useful if they are found unconscious or are unable to speak for themselves. Whoever clicks on the app (EMT for instance) can get the phone number of their emergency contact without entering into the App. This way, they don't have to compromise their confidentiality.

*Can anyone think of why do you need emergency contacts? (Invite all to share)
Fantastic!*

Who would you want to put as your emergency contacts? (Prompt the conversation by mentioning one of the following ideas: children, loved ones, etc.)

Now let's practice putting in your emergency contact information.

On this page, they can also enter their name, DOB, and other profile information such as Health Insurance, Employment, etc. You can prompt the conversation by mentioning why they should enter the information (saves time if someone else has to fill out their paper work, no need to memorize phone numbers and addresses, etc.) EMPHASIZE to them that this is part of the reason why they should have their App password protected.

Now you can also enter your personal information. Does anyone know why it is useful to have this info available? (Encourage answers)

Fantastic!

Now let's practice putting in your information.

D. INPUT ALLERGIES, TESTS AND PROCEDURES (30 MINUTES)

Inputting the information for these sections will be very similar to each other. You should use your projected iPad to show them how to add a new category by tapping on the plus sign or how to edit the information they already entered. You should also show them how to return to the main menu to move between each section.

Make sure they have plenty of time to practice. Have the assistant trainers walk around and make sure that the participants know how to enter data for each category.

Participants will start with height and weight, lifestyle and then move on immunizations and cancer screening.

The “Medication” and HIV testing sections will be deferred to the next session.

Now you can start entering all your health information.

There are five different sections: Allergies, Medications and Tests and Procedures, Health Problems, and Preventive Health.

Today I will show you how to use Allergies, Health Problems and Preventive Health. We will go over HIV medications and tests next session. First, can anyone tell me what the benefits of having this information are?

Awesome!

Now let's practice!

E. BACK-UP DATA/ RESTORE (5 MIN)

Take a few minutes to show them the back-up and restore feature. It is inactive at this time. But will become active in the near future. If they push it now nothing will happen.

F. REVIEW (15 MIN)

Take the time to review everything that they learned to day this should come from them.

Let's review what we went over today, who can tell us one thing we learned? And why it is important?

Excellent!

We went through a lot of new things today. Any questions?

For homework, play around with the application when you get home to get yourself familiar with the app and maybe you will discover something we didn't cover today. Some of you were unsure about the information you entered today. You should go back through it when you get home and double check that the info you entered is correct. If you have any questions or don't know how to do something, write it down and let me know next week! Be sure to bring in your HIV test results (CD4 count, viral load and list of your HIV medications for the next session.

Lesson 4: HIV Basics and Keeping Track

This session focuses on “HIV 101.” Participants will learn how the virus enters CD4 cells, replicates and how this process is related to tests (CD4 count) and viral load. It will also review how different classes of antiretroviral medications, e.g. Nukes, Non-Nukes, PIs, integrase inhibitors, and CCR5 inhibitors work and what the pills look like.

Learning Objectives for Session #4

1. To learn how the HIV virus acts on immune cells.
2. To learn how different tests work
3. To learn how different medications work
4. To correctly identify and enter own test values and medications in and use graphs.

Participants should be familiar with their PHR, This will introduce them to basic concepts that will enable them to effectively use their PHR app.

Activities

- a. Re-cap prior lesson and/or answer questions (10 minutes)
- b. HIV virus, CD4 cells and HIV tests (20 minutes)
- c. HIV medication actions (20 minutes)
- d. Entering tests and medications into PHR (15 minutes)
- e. Look at trends (personal cell counts, etc.) using graphs (10 minutes)
- f. Review (15 minutes)

A. RE-CAP PRIOR LESSON AND ANSWER QUESTIONS (10 MINUTES)

It is important that you go over the material that they learned from last week to refresh their memories and get them to feel comfortable using the devices again (in case they haven't been using the iPods). It is also a good idea to encourage them to ask questions about things that they can't figure out on their own. Share their questions with the class and encourage others to answer if they know. Make sure that there is no confusion or frustration at the beginning of the class this will make the participants feel more comfortable learning new things.

Before we start our new lesson, let's review what we learned last week. Does anyone want to show us something they remember how to do in ? Put in password?

Good.

Now, did you all finish your homework? Was everyone able to enter personal data into ?

Good.

Is there any question that you came across while doing your homework? (Give them time to ask questions)

Great!

B. HIV VIRUS, CD4 CELLS AND HIV TESTS (20 MINUTES)

This section will provide all patients with a basic understanding of the actions of the HIV virus and how it relates to their test results.

Let's talk about how HIV affects your immune system. Let's begin with your blood. Your blood is liquid with two main types of cells that "float around in this fluid throughout your body.

What are these two types of cells? Hint: they are different colors. Right! One type is a Red cell and the other is a White Cell. What do Red Blood Cells do? What about White Cells? CD4 or "T cells" are special type of White Cell. What do they do?

What does the HIV virus do to CD4 cells? Let me show you how the HIV virus attaches to the CD4 cell and then get inside and hijacks the cell headquarters. It then forces the cell into a slave cell that makes HIV virus before it dies.

Why does your doctor do CD4 count tests? What does it tell him or her? Why does it matter to you? Why does your doctor do viral load tests? What is this test? Why is it important?

C. HIV MEDICATION ACTIONS (20 MINUTES)

The next task is to show participants how HIV medications work, how they stop working and why taking their meds every single day is so important.

Let's talk about how the HIV medications – your cocktail-work. These medications work by blocking the virus at different points. Let me show you. What are different types of medications? What is a Nuke? Non-Nuke? A PI (Protease Inhibitor)? What is Norvir? Why is it given with most PIs?

Why are these medications given as “cocktails”? What happens if you take only one HIV medication at a time?

What is a combo pill? Can you give me some examples?

What happens when patients stop and start their HIV medications?

D. ENTERING TESTS AND MEDICATIONS INTO PHR (15 MINUTES)

The next task for participants is to enter their own CD4, viral test results from the past year along with their current HIV medications.

I want each of you to enter your CD4 and viral loads in . You all should have brought copies of your test results. If not, you can enter some “dummy” results for now and fix them when you get your real results.

We will have a helper come around to confirm you’ve done this correctly.

Now let's enter your medications.

E. LOOK AT TRENDS USING GRAPHS (10 MINUTES)

Graphs help patients see how their tests are changing over time. It is important to acknowledge that small dips are not necessarily meaningful. These are best discussed with one's clinician.

If you entered test results with more than one date, will provide a graph of your changes. In some cases, these changes don't mean much. In some cases, these do. These are good questions to ask your provider.

(Demonstrate on your iPad what the graphs look like and how to edit them)

Any questions?

F. REVIEW

Take the time to review everything that they learned today, this should come from them.

Let's review what we went over today, who can tell us one thing we learned? And why it is important?

Let's start with how the HIV acts. Who can summarize?

What is a CD4 cell? Why does it matter?

What is a viral load test?

How do HIV medications work?

Excellent! We went through a lot of new things today. Any questions?

For homework, play with your PHR when you get home to get yourself familiar with the App and maybe you will discover something we didn't cover today. Some of you were unsure about the information you entered today. You should go back through it when you get home and double check that the info you entered is correct.

Lesson 5: Asking questions that you want to ask

The goal of this lesson is provide participants with tools they can use to formulate questions for their doctor. In this lesson, participants will have the opportunity to role play and work in partners with their fellow participants. The role play session is intended to help participants rehearse question asking strategies they have learned.

Learning objectives

1. To understand why it is worth thinking about questions
2. To understand different types of questions
3. To practice asking questions with
4. To generate own questions
5. To practice asking questions with a partner

Activities

- a. Re-cap last week's lesson/answer questions (5 min)
- b. Why your questions matter (10 min)
- c. Reason patients don't ask question (10 min)
- d. Types of questions: Closed vs. Open (20min)
- e. Role Play (20 min)
- f. Group Share (20 min)
- g. Wrap-up (5 min)

A. RE-CAP OF LAST WEEKS LESSON/ANSWER QUESTIONS (5MIN)

Again, it is a good idea to encourage them to ask questions about things that they can't figure on their own. Share their questions with the class and encourage others to answer if they know. Make sure that there is no confusion or frustrations at the beginning of the class this will make the participants feel more comfortable learning new things.

Before we start our new lesson, does anyone have any questions?

Good.

Now, did anyone discover anything new they would like to share with the group?

Great!

B. WHY YOUR QUESTIONS MATTER (10 MIN)

The goal here is to show patients why THEIR questions are important

Let's talk about questions and how they can help you learn and how they can help you communicate better with your provider.

In one study, 78 percent of the 140 patients questioned did not understand instructions for their care after leaving the emergency room. Further, only 20 percent recognized that they had difficulties understanding information given to them. So if a patient doesn't know what he or she doesn't know, where do we go from here?

What are your thoughts about this? How could patients' questions help?

How have you learned about HIV? Where did you get your information? How can you be sure you learn about what you WANT?

Why is it important for patients to ask questions?

C. REASONS PATIENT DON'T ASK QUESTIONS (10 MINUTES)

In this part of the lesson, the goal will be to get participants to indicate reason why they or others they may know, do not ask questions of their doctor. There are no right or wrong answers. REMEMBER the goal in this part of the lesson is to generate reasons ONLY, not to come up with solutions. Participants may be tempted to offer ways to "fix" communication problems, but that is not the purpose of this lesson. Remind them of that if they begin to get off track. Encourage EVERYONE to share.

If questions are so important, why don't many patients ask?

What could help people to ask questions they WANT answers to?

D. TYPES OF QUESTIONS: CLOSED VS OPEN (20MIN)

In this part of the lesson, the goal is to teach participants the difference between open ended and closed ended questions. Many of the participants may already know what this means. Encourage them to help you with this part of the lesson.

Can anyone tell me the difference between an Open and Closed ended question?

How are they useful?

Give me an example of each?

Thanks for sharing!

(If no one knows): A closed ended question is one that requires a simple yes or no answer. Such as, is it raining? Are you in class today? Do you like pizza? An open ended question requires a more detailed response. For example, what kinds of toppings do you like on your pizza? What are you learning in class to do?

Both can be useful, but when we are trying to make decisions, especially ones regarding our health, we need to be aware of what information we need to make a decision. For example, if I am a smoker and a friend of mine died last week from smoking complications. I am now concerned I may die as well. My question for my doctor isn't necessarily can smoking kill me (closed), because I know it will. My question is what do I need to do so that I do not die? Or how likely am I to end up like my friend if I don't stop smoking immediately? Or what are my options to help me quit? (Open ended)

Does everyone understand?

E. ROLE PLAY (20 MIN)

Once you are confident that the group understands the difference between open and closed ended questions, you can have them break into groups of two to complete the next assignment. The goal of this assignment will be to create 3 questions that they would like to ask their providers either at their next appointment or some point in the future. They should enter their questions in the PHR under To Ask List in the App and practice asking the questions with their partner. One participant will play the doctor and the other will play the patient. Each will get a chance to play both roles.

*Use the
Asking
Questions
workshee
t

Now we are going to break into groups of two to practice creating questions and saying them out loud.

I need a volunteer to help me demonstrate what we are going to do? Anyone?

Thanks!

Ok, so the first thing you will need to do is write down 3 questions that you would like to ask your doctor either at your next visit or sometime in the future. Then enter the questions into your UR Health To Ask List. I have already written mine in my .

After that we will give our partner a little background on why we are interested in asking these questions...

Make sure you move your questions to the top of your To Ask List.

Next we are going to practice saying them out loud. We all know how hard this can be sometimes. So...I will play the patient, and you will play the doctor. (Share your question)

Then you will reverse, so that means I would play the doctor next.

Once you have asked your questions, ask your partner if they feel you will get the answers you want, based on the questions you asked. This is why providing background on why you are asking the questions is important.

Keep the idea of open vs. closed ended questions in your head. Do you have all of one type of question? Will it get you the info you need to make a good decision? Do you need to tweak your questions? If so, go ahead and do so.

Finally, you will choose your "best question" you came up with to share with the group.

The trainers will walk around and help you out in case you get stuck. Any questions?

Great, everyone choose a partner and I will pass out the worksheet.

F. GROUP SHARE (20 MIN)

After about 20 minutes you should have them wrap up. The rest of the day will be spent having the participants share their questions they came up with and how they felt going through the process. Encourage them to share if they had to change their questions and why. Be positive about even partial completion of the assignment, and give positive feedback for anything they are able to contribute to the group. It is not easy to share with a group.

G. WRAP-UP (5 MIN)

Wrap-up by thanking the participants for sharing all of the questions and remind them about confidentiality.

You guys did great today. We shared a lot of personal information so...

As a reminder it is important that everyone understand that what we talk about in class is private, and who we see in class is private. We all signed a confidentiality agreement during the consenting process saying that we were not going to share what happens in class with anyone else, and we are all being held to that. This includes sharing who you see here and what they say with your doctor, social worker, psychiatrist, therapist, mother, father, etc.

Any questions?

For homework, think of any other questions you may want to ask your doctor? May sure the questions are worded in a way that you will get the answer you want from your provider. Add the questions to your To Ask List in UR Health.

Lesson # 6: APPS and Wrap-up

The goal of this lesson is for participants to learn about free apps that can help them manage their health.

Learning objectives

1. To learn about iTunes/App Store
2. To learn about apps and how they can help
3. To learn how to download Apps
4. To learn how to use AIDSinfo Glossary and MyFitness Pal
5. To learn how to use other Apps

Activities

- a) Recap (15 min)
- b) AIDSinfo Glossary and iTunes/App Store (15 min)
- c) Practice using MyFitness Pal (10 min)
- d) Practice using other Apps (15 min)
- e) Recap of training (15min)
- f) Certificates

A. RE-CAP LAST CLASS AND REVIEW ASKING QUESTIONS (15MIN)

Go over whether they have done their homework and added to their To Ask List; encourage them if they have done so. However, don't be discouraging toward participants if they have not done their homework. Emphasize that this will only help them if they put time and effort in to it. Also, ask them what they have done with their iPod's on their own time.

Before we start our new lesson, let's review what we learned last week. What is the difference between Open and Closed ended questions? Can anyone give me an example of each type of question?

Great!

Now, did you all finish your homework? Was everyone able to enter more questions to ask your provider into ?

Good.

*Are there any questions that you came across while doing your homework?
(Give them time to ask questions)*

Great!

B. AIDSinFO GLOSSARY AND ITUNES/APP STORE

Participants need to learn how to navigate the iTunes/App store so they can find Apps useful to them.

Some of you may have noticed that some of the websites mention that the APP is available for download. The next thing we are going to do is learn to download APPs. Let's begin by downloading the AIDSinFO Glossary App. Go to your Safari and type in <http://www.aidsinfo.nih.gov/>. Press the GO button. Scroll down to the bottom of the screen and tap Mobile Resources & Tools. Now tap the word Apps. Now scroll down to the bottom and tap the Download the Glossary App for your iPod Touch icon. Now tap the cloud with the arrow in it. (Demonstrate)

Now we will just need to wait for a few minutes for it to download. Downloading the APP saves us time, so that we don't have to type in the web address each time. The App will automatically appear on our iPods, see. (Demonstrate once it has downloaded)

Open the app. Now let's look for the definition of a term we talked about during our HIV Basics session. In the search bar, enter Protease Inhibitor. Now select it. We can see what it means. We can even tap the icon next to the word and the app will pronounce it for us.

Do you want to try another term?

Great!

We can also download some Apps from the App Store and iTunes icons. Can anyone find those on the HOME screen?

Great!

Now locate and tap the App Store icon. There is a section at the top left of your screen which says Categories. (Let them explore) At the bottom of the screen you should see 5 icons. (Explain them briefly)

C. PRACTICE USING MY FITNESS PAL

We will now download another helpful app, My Fitness Pal, directly from the App Store. Tap the Search icon located at the bottom of your Home screen. Tap the search bar and enter my fitness pal. Tap the free icon. Now tap INSTALL APP. (While the app is downloading explain the use of the app) When you see open, that means the download is complete. Tap open.

(Demonstrate how to put information in the app. Input the snack that was served to the participants in the diary portion of the app. Let participants practice.)

Great job everyone!

D. PRACTICE USING OTHER APPS

The participants REALLY enjoy this part of the training. Let them take the lead during this part of the lesson. Many of them will have downloaded Apps and or music already and are eager to share what they have found with the rest of the class. You can have them find the few Apps on the Apps and Sites hand-out as a group to get them comfortable searching on their own. Point out some Apps are free and some need to be purchased. Identify how they can purchase an APP (credit card, debit card, iTunes gift card). You will also want to have their iTunes password available, they will need these to begin downloading. They will likely have forgotten what this password is as well. These passwords should be in their consenting packets.

Has anyone downloaded any good Apps? It can be games, health, etc.

Good.

Now let's browse the App store and see what we can find. You don't have to download anything today, we are just doing an overview of how to find Apps and how to download/pay for an App. Again, if you want more help you can get that during an extra help session.

I am happy you guys enjoyed this part of the training so much.

Any questions?

E. RECAP OF TRAINING

E. RECAP OF TRAINING

Spend a few minutes with an overall summary

END OF GROUP TRAINING

The G.R.E.A.T. iPod training program although brief in duration, may still produce a bond between the participants and the trainer(s). The last session should end with a celebration of the work accomplished together. Trainers should expect some of the feelings that may surface such as uncertainty, anxiety, pride, and optimism. You can help by reminding participants of the tools they developed to make independent choices in their healthcare. Ideally participants will continue to work on the skills they learned and think of even more ways to use their iPods and communication skills.

Allow participants a chance to reflect on what they have learned, in their own words.

What has been most helpful about the trainings? Least helpful? If you could, would you change anything? If so, what would it be?

After participants finish reflecting, note any feedback they gave you. This could be useful in the development of future training sessions. Emphasize resources in the community where the participants can get help if they need it (free Wi-Fi locations, apple store, online).

Even if participants haven't mastered all of the skills that were taught, it is possible that they will as they have time to practice and use the tools in the real world. In still this hope and expectation as you wrap up.

F. CERTIFICATES

End training with best wishes for the future.

You have been a great class! I am very proud of you. I'd like to give each of you a certificate for your completion. If you'd prefer not receive one let me know.

Individual Coaching Session: Putting it into action

This one-on-one coaching session is designed to assist patients in putting their lessons into action during a visit with their HIV clinician. This means making sure the participant comes prepared with their iPod and their questions. This session is intended to translate the lessons from the group training into practice.

Action objectives

1. Assist participants to prepare for their office visit
2. Assist participants to prepare questions they wish to ask
3. Assist participants to ask their questions

Activities

- A. Before the coaching session (3 MIN)
 - a) Call participants before office visit and arrange a time and place to meet for the coaching session
 - b) Remind the participant to bring their iPod to the coaching session
- B. During the coaching session (70 minutes)
 - c) At the coaching session, ask the participants to briefly review their ePHR and their questions.
 - d) Ask the participants to prioritize their questions
 - e) Participant completes post survey (if it has not already been completed)

A. BEFORE THE COACHING SESSION

Confirm with office staff that the participant has an office visit within the next week. Call the participant 5-7 days before their office visit to arrange for a coaching session. This will allow time needed to contact participants and also will facilitate scheduling a time that is convenient for the participant.

Hi I am ____ I am your coach from the iPod program. I was the trainer. I was calling to set up a coaching session before your office visit with Dr____. Can we do that? What time and place would work best for you?

Do you still have your iPod? Is it working? Please make a note to bring it with you to (or have it available for) your coaching session with me. (If the iPod is no longer available, continue to make arrangements to meet.) That's OK if it is broken (lost). I still would like to meet with you and go over (or discuss) questions you might have for Dr____.

Think about questions you want to ask Dr__ and add them to your "To Ask List" in UR Health. Do you remember how to do that? If not, we can work on it together when meet (or on our next call).

Now to confirm we will meet (or talk again) on (date & time) at (place). If you have to cancel due to an emergency, please call. Don't forget to bring your iPod (or have your iPod available). Please the next afternoon I will

B. DURING THE COACHING SESSION

Ensure you have a private space to meet with the participant.

Hi, _____. I am _____. I am your coach from the iPod program.

Do you have your iPod? Is it working? Have you had the chance to use it since the training? What parts have you used? Great!

First, I want to give you a (or First, I want you take out the mailed) copy of the Values Affirmation you filled out during the consent process for this study. Just read over what you wrote and think about why they are important to you. (5 minutes)

*Use the
Communi-
cation
Tips
Sheet

Great! Now we're going to talk about some communication tips. (10 minutes)

Give participant a (or Have participant take out) copy of the Communication Tips: Individual Coaching Sheet Hand-out. Go over hand-out with participant to make sure participant understands effective patient-doctor communications. Afterwards proceed with the following question and remainder of session.

Have you entered questions you want to ask Dr_____?

Let's go over them. Which one is the most important one to you? Let's make it the first question. Do you remember how to do it? Do you have other questions?

Great! We suggest patients to think about their top three questions. Depending on much time it takes for your doctor to answer, you might be able to ask more.

*Use Role
Play
Scenarios

Use role play scenarios for this next portion.

Let's practice asking them. I will pretend to be the doctor. I want you ask me your questions just like you will with Dr_____. Great! Now ask me your next question.

Let's imagine, that Dr_____ seems like s/he is in a hurry today. How can you be sure you are heard? What can you say? Let's try it out. Great!

After you complete the role play scenarios determine if participant has any other study related questions you did not participate. If so, answer the questions or tell participant you will get back to him/her with the answer.

Now have participant complete the post survey if still necessary

G.R.E.A.T iPod TRAINING PROGRAM

Participant Commitment Form

PLEASE PRINT:

LAST NAME: _____ **FIRST NAME:** _____

I understand taking part in this research study is voluntary (my choice). With this in mind, I am committing myself to the following:

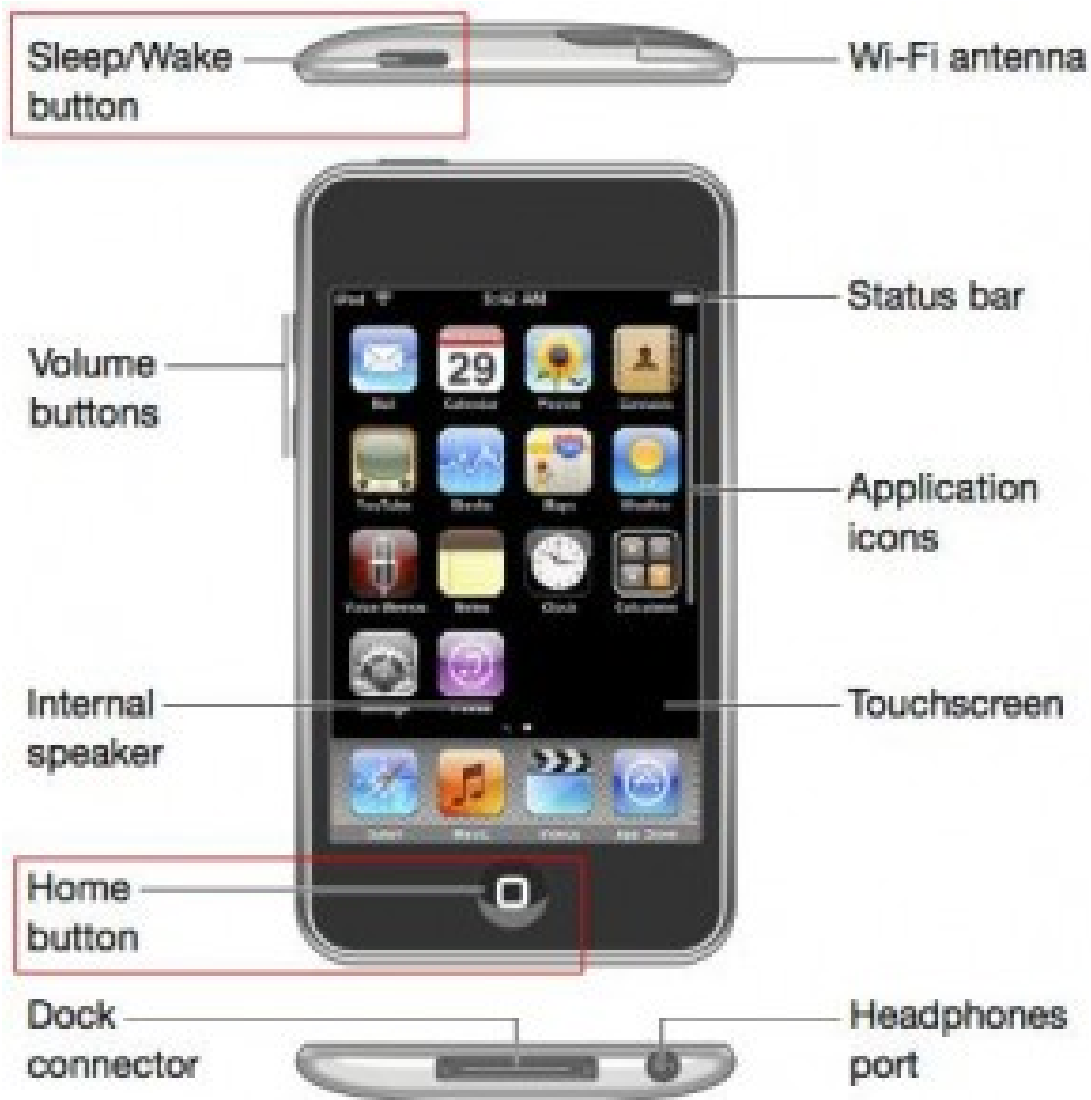
1. I will attend all the required training sessions and complete all study activities including homework.
2. I will be on time and be ready to participate. I will call the trainer before the scheduled start time if I cannot attend a session. I understand that missing two training sessions is one of the reasons for being dropped from the study.
3. I will contact research staff with any changes in my contact information, specifically my primary phone number and address.
4. I will maintain confidentiality by not sharing who I see in the program or what they say with anyone including my doctor, social worker, other care providers, friends or family members.
5. I will not attend the training sessions under the influence of alcohol or drugs.
6. I will be respectful and have a positive attitude towards other participants and staff. I will not read email, text, surf the internet or talk while others are speaking. I will not be disruptive, make disrespectful faces and/or sounds. I also will limit the length of my sharing.
7. I understand that if I leave this study for any reason, whether it's my choice or I have been dropped, I am **required to return the iPod**.

IMPORTANT: Taking part in this research study is your choice. You are free not to participate or to withdraw at any time, for whatever reason. No matter what decision you make, there will be no penalty, loss of benefit to which you are entitled or negative effect on the care and services you receive. In the event that you do withdraw from this study, the information you have already provided will be kept confidential, and you will be **required to return your iPod**.

You will also be **required to return your iPod** in the event you are dropped from the study with cause, such as: for not attending all the required training sessions, completing all study activities, being under the influence of alcohol or drugs, misconduct or if the study sponsor decides to stop or cancel the study.

Participant's Signature: _____ **Date:** _____

WHERE IS IT?



Websites, Apps

SITES

MEDILINE PLUS: <http://www.nlm.nih.gov/medlineplus/>

AIDSINFO: <http://www.aidsinfo.nih.gov/>

AIDS/HIV INFO: <http://www.thebody.com/>

APPS

MYFITNESS PAL

iTRIAGE

FIND MY IPOD

EMAIL PROTECTION TIPS

Helping you fight identity theft from occurring through your email accounts

Protect your email account before something happens

- **Use a strong password.** Create a password with letters, upper and lower case, numbers and special characters such as #, &, and %. Don't use your first or last name as part of your password or a phrase that is easy to guess.
- **Protect your address and password.** Your email ID and password are your confidential information. Don't tell anyone your password or give them a clue to your password. Do not keep a copy of your email details on the internet or on your system.
- **Use the second sign-in verification option if it is available from your email provider.** This option looks for suspicious sign in attempts from a new browser other than the one that you originally used to enable this option. If there is a suspicious attempt, the person will need to enter a verification code that will be sent to your cell phone or will need to answer two security questions that you established as part of the process. If you weren't trying to access your account and you receive the code, you'll also know that someone was trying to access your account.
- **Don't click on links in an unsolicited email.** Legitimate companies never send an email asking you to reset your password or provide personal information by clicking on a link. If you receive an unsolicited email asking you to click on a link, don't. Instead, go to the company's website to access your account.
- **Protect your computer.** Install a good anti-spyware program and update it regularly.
- **Take caution with public computers and Wi-Fi.** If possible, avoid using public computers to access anything sensitive, such as conducting online banking, making purchases, or accessing email accounts. These computers could potentially have malware that is designed to capture the information you have entered. Avoid these same activities when using a public Wi-Fi connection as the information can easily be captured by criminals on the same connection. Make sure to use an encrypted Internet connection whenever you go online.

Signs that your email has been hacked

- Your inbox is full of Mailer-Daemon rejection notices.
- Your contacts are getting mail from you that you did not send.
- There are outgoing messages in your Sent, Drafts or Outbox folder that you didn't send or create.
- Your Address Book contacts have been erased or there are contacts that you did not add.
- Emails you try to send are suddenly getting refused and returned to you.

- You keep getting bumped offline when you're signed into your account.
- You are not getting new mail, or your new mail is going straight into your Saved Ims folder.

EMAIL Tips

Recover your email after you've been hacked

Step 1: Change your password

If you're able to log into your account (some hackers actually forget to change your password on you), then do so and change your password immediately.

Step 2: Regain control of your account(s)

If you're unable to access your account, follow the directions on the email site help center. Remember to change your security and answer questions once you have regained control as the hacker may have noted this information.

Step 3: Report It

Report it to the site immediately.

Step 4: Communicate with your audience

Notify all of your email contacts so they can protect themselves. If emails were sent to your contacts by the hacker, send out an apology to any contacts who might have been the victim of your email hack. Explain what happened and advise your contacts that emails sent from your address might contain dangerous software so that they can protect their computers.

Other Things to Consider

Scan your computer with an updated anti-virus program. It is possible that a Trojan, which runs in the background of your computer systems, was slipped in when your email account was compromised. Hackers can obtain your passwords or gain access to personal information through the Trojans. Run your antivirus program and remove any viruses, spyware, or malware that is identified. If you don't have an up to date antivirus program we recommend that you install one immediately.

Review your internal email settings. Check for forwarding email addresses and delete any addresses that are not yours.

Check for a signature, which is personalized text that is automatically inserted at the bottom of every message you send, and delete if it is not yours.

Change the password on all accounts that you used the same hacked password on.

- Other Email accounts
- Financial accounts
- Online Merchant accounts
- Social Media accounts

Review your email folders for any data exposure. Check all folders for emails that may contain personal or account information. If you find any, immediately change the user id and passwords and contact your fraud specialist for further guidance.

Information retrieved from:

<http://www.idt911.com/KnowledgeCenter/ProtectYourself/TipDetail.aspx?a=%7BDB1A17F8-252E-480B-B704-8DD310754390%7D>

ASKING QUESTIONS

3 questions I would like to ask my doctor are:

1. _____

2. _____

3. _____

1st Provide your partner with a little background on why you are asking these questions.

2nd Role Play: Practice asking your questions with your partner. You play the patient and your partner should play the doctor. When you are done reverse roles.

3rd Discussion: With your partner, decide if you need to change any of your questions. Were your questions primarily open or closed? Will your questions help provide you with the information you need to make your decision?

Notes: _____

The question I am sharing with the group is:

Group Members: _____

Date: _____

Communication Tips: Coaching Session

Taken from: <http://patients.about.com/od/therightdoctorforyou/a/docpatientcomm.htm>

Effective Patient - Doctor Communications

By Trisha Torrey, About.com Guide

Updated September 13, 2011

There are more challenges than ever in today's healthcare environment. Limited appointment time, the ability of patients to do their own research which then needs to be discussed with practitioners, and the numbers of patients who are undiagnosed or misdiagnosed; these challenges and others make effective communications between patients and their practitioners more important than ever.

Good communications really boils down to two things: **respect for each other, and the ability to manage expectations.**

The following will help you understand how to be a good communicator yourself, and what to expect from a practitioner who is a good communicator.

A patient who is a good communicator:

- **Will be mindful of the doctor's limited time.** While some references tell us a patient has an average of only 8-10 minutes per appointment with his doctor, other references say the average is 16-20 minutes. The discrepancy may be due to the kind of visit, whether the doctor is primary care or a specialist, or even health insurance coverage. Regardless of the difference, it makes most sense for us patients to prepare ahead for the probability that the visit will be shorter than we expect. ([Why Won't My Doctor Spend Enough Time with Me?](#))
- **Will be concise in his communication,** preparing carefully for meetings with his practitioner. A well-organized patient prepares questions ahead of appointments, and sticks to the facts. With so little appointment time, you'll want to be sure your doctor has all the important information about your problems, and has time to answer all your questions.
- **Will ask the meaning of words and concepts he doesn't understand.** Doctors are trained to use a lexicon of med-speak that baffles us patients. General medical terms are used by all doctors or many specialties. Other words and concepts are specific to body systems, conditions, diseases or treatments. In all cases, you'll walk away much more satisfied from your visit, having learned what you need to know, if you stop your doctor and ask for a definition or description when he uses a concept or term you don't understand.

- **If interrupted, will ask the doctor to stop and listen respectfully.** Some studies say it takes only 23 seconds before a doctor interrupts his patient. Dr. Jerome Groopman, author of *How Doctors Think*, states that doctors interrupt their patients within 18 seconds of the start of their conversation. If your doctor interrupts you, it can feel like an insult. Politely ask him to listen to your entire list of symptoms, or to let you ask your entire question. Sometimes a simple gesture such as gently holding up your hand will alert your doctor to stop and listen to you.
- **Will ask his doctor what to expect next.** No matter what point you are in your transition through the system: before, during or after diagnosis or treatment, asking your doctor what happens next will help you understand what is going on immediately, and what your outcomes might be. For example, if your doctor says he is sending you for a medical test, you might ask what he expects the results will be, or what the possible outcomes might be, and what they would mean. If he can manage your expectations, you will have more confidence about the process and its outcomes.
- **Will know which questions to ask the doctor, and which to save for others.** Your doctor is the person who should answer any of your medical questions. But other questions, such as directions to a testing center, or the time of your next appointment, or where you should park your car, can be asked of others on the doctor's staff. That conserves your short appointment time for the important, medical aspects of your care.

A doctor or practitioner who is a good communicator:

- **Has respect for her patient.** Good doctors understand that a sick or injured patient is highly vulnerable. Being respectful goes a long way toward helping that patient explain symptoms, take responsibility for decision-making, and complying with instructions.
- **Has the ability to share information in terms her patients can understand.** It's OK to use med-speak and complicated terms, but they should be accompanied by an explanation at the same time.
- **Doesn't interrupt or stereotype her patients.** It's easy for all of us to interrupt when we know time is short or we are in a hurry, but a practitioner who is a good communicator knows that if it can't be done right to begin with, it will need to be done over. Listening carefully and respectfully will go a long way toward better outcomes for the patient.
- **Has the ability to effectively manage patients' expectations.** By helping her patient understand what the next steps will be, and what the possible outcomes and their ramifications might be, the doctor can go a long way toward helping that patient understand his problem.

What to Do If Your Communications with Your Doctor Don't Work Well

Sometimes, despite our best attempts, we just can't establish that rapport with our doctors. The problem may be with our own approach, or it could be the doctor's communications style. Here are some resources for helping you decide what to do if you and your doctor don't communicate well.

ROLE PLAY SCENARIOS

INTRODUCING QUESTIONS

Coach: It is important to that you prepare for your doctor's visit by practicing how you will ask your questions. Do you remember some of the approaches we used? Many participants bring up their questions during the first minute of the visit. Can we try it out? I'll play your doctor...

Participant: OK

Coach: Good morning, Charles. I am your doctor. How have you been doing?

Participant: I've been OK. Before we get started I wanted to let you know I have three questions I hoped we could discuss today. Is that alright?

Coach: Sure. Let's get them out now and we can start with the one that is most important to you.

Participant: I put them down on my iPod. Let me bring them up...

Coach: That was perfect. Let's do a role play that is a bit harder. Are you willing?

GETTING YOUR CLINICIAN'S ATTENTION

Coach: Good morning, Charles. How have you been doing?

Participant: I've been OK. Before we get started I wanted to let you know I have three questions I hoped we could discuss today. Is that alright?

Coach: Sure. But first I want to go over your weight. You've gained 30 lbs. over the past year. Can you tell me what you have been eating?

Participant: I haven't been following that diet you gave me. I know what I need to do. Can we first go over my questions? They are more important to me right now than my weight.

Coach: Excellent. You were persistent and made your needs known.

PROBLEM SOLVING

Coach: Good morning, Charles. How have you been doing?

Participant: I've been OK. Before we get started I wanted to let you know I have a three questions I hoped we could discuss today. Is that alright?

Coach: Sure. But first I want to go over your weight. You've gained 30 lbs. over the past year. Can you tell me what you have been eating?

Participant: I haven't been following that diet you gave me. I am still eating at McDonalds a lot. Healthy food seems expensive and it doesn't have much taste.

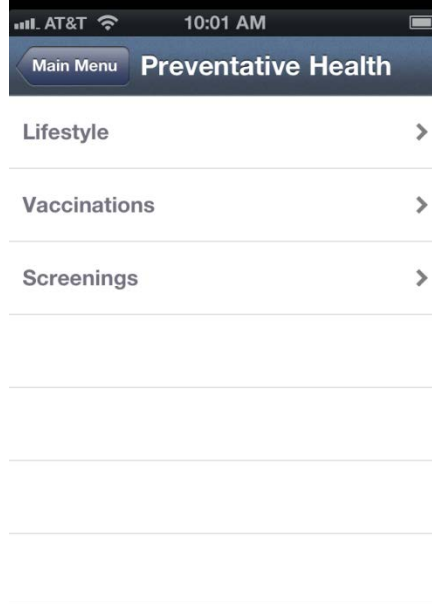
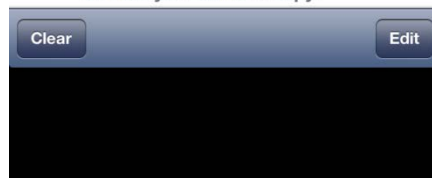
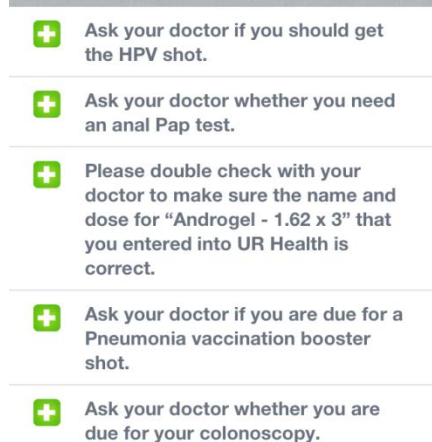
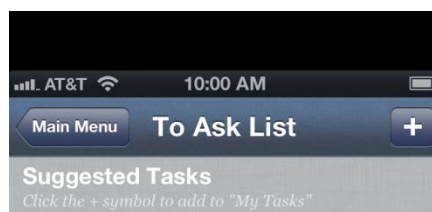
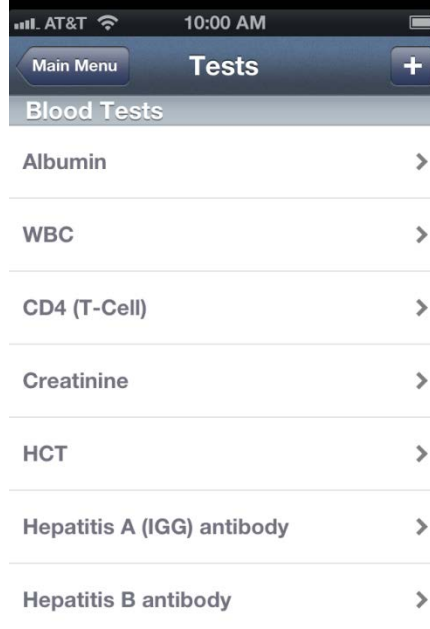
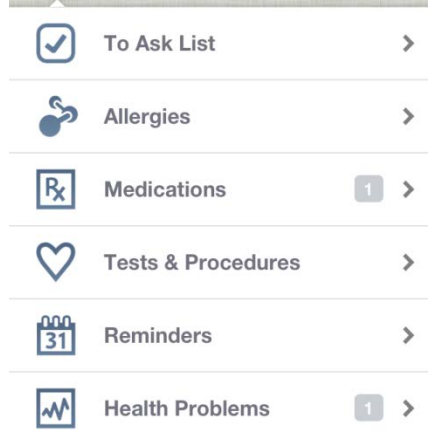
Coach: You could try cooking at home. It doesn't cost as much as you think. For example.....Coach calls time out.

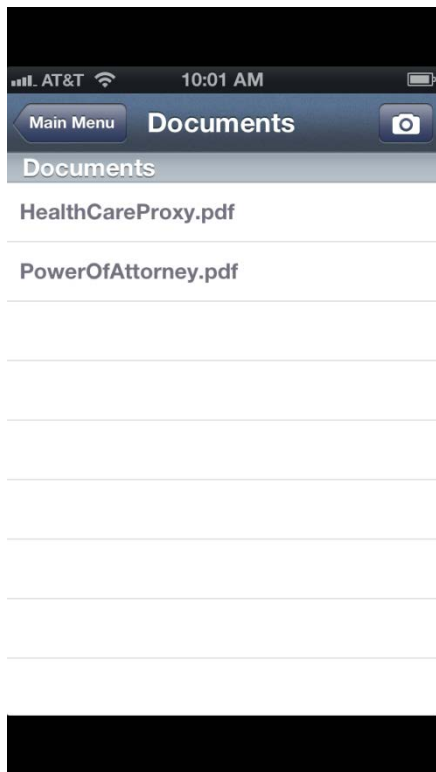
Coach: What could you say to get the conversation back on track on your questions?

Participant: I could tell the doctor I know I need to work on my diet but don't want to talk about it about it right now...

Coach: Great. Let's try it.

UR-HEALTH SCREEN SHOTS





MEDICAL ABSTRACTION FORM

Date: ___/___/___
Time Started: _____

**NOTE TO REVIEWER: PLEASE USE GUIDE FOR
CHART ABSTRACTION TO HELP COMPLETE**

☐ AJHC ☐ Morris H. ☐ Other: _____
☐ Horizon Health ☐ SMH
☐ LFHC ☐ Trillium
☐ Metro ☐ Unity

Subject ID (CDN/URMC)		Unique ID (Sites)		
Start of Enrollment Date		END Date Of Enrollment		
Gender: ___ Male ___ Female ___ Transgender		If Transgender: ___ MTF or ___ FTM		

NOTE: If you can't find a data point, please write in "Can't find".

Immunizations					
	Variable Label	Response Values	Prior to Enrollment date	Post Enrollment date	Collection Date
1.	Human Papilloma Virus (HPV)	<input type="checkbox"/> Series started and complete <input type="checkbox"/> Series and incomplete. <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____	___/___/___

2.	Influenza/ Flu	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence <input type="checkbox"/> Nasal spray (date:_____)	<input type="checkbox"/> Shot Date _____	<input type="checkbox"/> Shot Date _____	____/____/____
	Variable Label	Response Values	Prior to Enrollment Date	Post to Enrollment Date	Collection Date
3.	Pneumococcal Pneumonia	<input type="checkbox"/> Yes *if two shots listed give date of latest shot Type: <input type="checkbox"/> 23 <input type="checkbox"/> 13 <input type="checkbox"/> Other _____ <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> 23 Shot Date _____ <input type="checkbox"/> 13 Shot Date _____ <input type="checkbox"/> Other Shot Date _____	<input type="checkbox"/> 23 Shot Date _____ <input type="checkbox"/> 13 Shot Date _____ <input type="checkbox"/> Other Shot Date _____	____/____/____
4.	Tetanus and Diphtheria Toxoid (Td, Tdap) 1. Lockjaw 2. Diphtheria	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Shot Date #1 _____	<input type="checkbox"/> Shot Date #2 _____	____/____/____

5.	Hepatitis A virus (HAV) Hepatitis A	<input type="checkbox"/> Series started and completed <input type="checkbox"/> Series started but incomplete # Of Shots Administered _____ <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____	<input type="checkbox"/> Date #1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____	____/____/____
	Variable Label	Response Values	Prior to Enrollment Date	Post to Enrollment Date	Collection Date

6.	Hepatitis B virus (HBV)	<input type="checkbox"/> Series started and completed <input type="checkbox"/> Series started but incomplete # Of Shots Administered _____ <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____ <input type="checkbox"/> Additional Shot Date _____	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____	____/____/____
----	--------------------------------	---	--	---	----------------

7.	Hepatitis A & Hepatitis B <u>combined vaccine</u> (Twinrix)	<input type="checkbox"/> Series started and completed <input type="checkbox"/> Series started but incomplete # Of Shots administered _____ <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____ <input type="checkbox"/> Additional Shot Date _____	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____	____/____/____
Hepatitis C Treatment					
	Variable Label	Response Values	Prior to Enrollment Date	Post to Enrollment Date	Collection Date

8.	Hepatitis C Treatment (HCV)	<input type="checkbox"/> Antiviral Tx Started and completed <input type="checkbox"/> Antiviral Tx Started and incomplete <input type="checkbox"/> No Evidence <input type="checkbox"/> N/A if have not tested positive for HCV	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____ <input type="checkbox"/> No Evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Date # 3 _____ <input type="checkbox"/> No Evidence	____/____/____
Hepatitis Labs /Blood Test					
	Variable Label	Response Values	Prior to Enrollment Date	Post to Enrollment Date	Collection Date
9.	Hepatitis A (HAV)	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Positive <input type="checkbox"/> Negative	<input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Positive <input type="checkbox"/> Negative	____/____/____

	Variable Label	Response Values	Prior to Enrollment Date	Post to Enrollment Date	Collection Date
10.	Hepatitis B (HBV)	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	____/____/____

11.	Hepatitis C (HCV)	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 2 _____ <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> No evidence	____/____/____
HIV Care					
	Variable Label	Response Values	Prior to Enrollment Date	Post Enrollment Date	Collection Date

12.	Viral Load <i>-as of their date of enrollment in the study</i>	<input type="checkbox"/> Detectable <input type="checkbox"/> Undetectable <input type="checkbox"/> No evidence	<input type="checkbox"/> Detectable Test Date # 1 _____ Copies /ml _____ <input type="checkbox"/> Undetectable Test Date # 2 _____ Copies /ml _____ <input type="checkbox"/> No evidence	<input type="checkbox"/> Detectable Test Date # 1 _____ Copies/ml _____ <input type="checkbox"/> Undetectable Test Date #2 _____ Copies /ml _____ <input type="checkbox"/> No evidence	____/____/____
13.	T-Cell CD4 <i>-as of their date Of enrollment in study</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____ Count _____ % _____	<input type="checkbox"/> Date # 2 _____ Count _____ % _____	____/____/____
Cancer Screening					
	Variable Label	Response Values	Prior to Enrollment Date	Post Enrollment Date	Collection Date

14.	Mammogram	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	____/____/____
	Variable Label	Response values	Prior to Enrollment Date	Post Enrollment Date	Collection Date
15.	Colonoscopy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	____/____/____
16.	Fecal Occult Blood Test (FOBT) Fecal Immunochemical Test	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	____/____/____
17.	Cervical/Pap (UTD)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	____/____/____

18.	Hysterectomy	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence <input type="checkbox"/> N/A			__/__/__
19.	Anal/Pap	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	__/__/__
	Variable Label	Response values	Prior to Enrollment Date	Post Enrollment Date	Collection Date
20.	Low Dose CT scan	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No evidence	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	__/__/__
21.	DEXA scan	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Date # 1 _____	<input type="checkbox"/> Date # 2 _____	__/__/__

		<input type="checkbox"/> No evidence			
Other					
22.	Date of HIV diagnosis	Date: _____	Date of AIDS diagnosis (not just HIV positive)	Date : _____	___/___/___
	Variable Label	Response values	Prior to Enrollment Date	Post Enrollment Date	Collection Date
23.	<i>Low-density lipoprotein</i>	<i>(LDL Cholesterol)</i>	_____mg/DL _____ Date #1	_____mg /DL _____ Date #2	___/___/___
24.	<i>High-density lipoprotein</i>	<i>(HDL Cholesterol)</i>	_____mg/DL _____ Date #1	_____mg/DL _____ Date #2	___/___/___

_____ check here if there are NO comorbidities to report.

COMORBIDITIES: Taken from the visit summary or problem list on the day of the last visit to the health center. Please place a check in the yellow box next to all that apply.

	AIDS (not just HIV positive)		Liver Disease (moderate or severe)
	Cerebrovascular Disease: CVA with mild or residual TIA		Lymphoma
	Chronic Pulmonary Disease		Metastatic Solid Tumor (cancer)
	Congestive Heart Failure (CHF)		Mild Liver Disease (without portal hypertension, include chronic hepatitis)
	Connective Tissue Disease		Myocardial Infarction (history no ECG changes only)
	Dementia		Peptic Ulcer Disease
	Diabetes with end-organ damage (retinopathy, neuropathy, or brittle diabetes)		Peripheral Disease (includes aortic aneurysm $\geq 6\text{cm}$)
	Diabetes without end-organ damage excludes diet-controlled alone)		Renal Disease (moderate or severe)
	Hemiplegia		Tumor (cancer) without metastasis (exclude if > 5 years from cancer diagnosis)
	Leukemia		

☐ Other comorbidities:_____

☐ Deceased Date:____/____/____ (If Known)

Additional Notes:

Abstractor Initials: _____

Date:_____ Time Ended:_____AM/PM

Diagnostic categories, original ICD-9-CM codes, and corresponding ICD-10-AM codes

Condition	Codes	
	ICD-9-CM	ICD-10-AM
Acute myocardial infarction	410, 412	I21, I22, I252
Congestive heart failure	428	I50
Peripheral vascular disease	441, 4439, 7854, V434	I71, I790, I739, R02, Z958, Z959
Cerebral vascular accident	430–438	I60, I61, I62, I63, I65, I66, G450, G451, G452, G458, G459, G46, I64, G454, I670, I671, I672, I674, I675, I676, I677, I678, I679, I681, I682, I688, I69
Dementia	290	F00, F01, F02, F051
Pulmonary disease	490, 491, 492, 493, 494, 495, 496, 500, 501, 502, 503, 504, 505	J40, J41, J42, J44, J43, J45, J46, J47, J67, J44, J60, J61, J62, J63, J66, J64, J65
Connective tissue disorder	7100, 7101, 7104, 7140, 7141, 7142, 71481(now 5171), 725	M32, M34, M332, M053, M058, M059, M060, M063, M069, M050, M052, M051, M353
Peptic ulcer	531, 532, 533, 534	K25, K26, K27, K28
Liver disease	5712, 5714, 5715, 5716	K702, K703, K73, K717, K740, K742, K746, K743, K744, K745
Diabetes	25002501, 2502, 2503, 2507	E109, E119, E139, E149, E101, E111, E131, E141, E105, E115, E135, E145
Diabetes complications	2504, 2505, 2506	E102, E112, E132, E142 E103, E113, E133, E143 E104, E114, E134, E144
Paraplegia	342, 3441	G81 G041, G820, G821, G822
Renal disease	582, 5830, 5831, 5832, 5833, 5835, 5836, 5837, 5834, 585586588	N03, N052, N053, N054, N055, N056, N072, N073, N074, N01, N18, N19, N25
Cancer	14, 15, 16, 18, 170, 171, 172, 174, 175, 176, 179, 190, 191, 192, 193, 194, 1950, 1951, 1952, 1953, 1954, 1955, 1958, 200, 201, 202, 203, 204, 205, 206, 207, 208	C0, C1, C2, C3, C40, C41, C43, C45, C46, C47, C48, C49, C5, C6, C70, C71, C72, C73, C74, C75, C76, C80, C81, C82, C83, C84, C85, C883, C887, C889, C900, C901, C91, C92, C93, C940, C941, C942, C943, C9451, C947, C95, C96
Metastatic cancer	196, 197, 198, 1990, 1991	C77, C78, C79, C80
Severe liver disease	5722, 5723, 5724, 5728	K729, K766, K767, K721
HIV	042, 043, 044	B20, B21, B22, B23, B24

Table 8 (appendix). Effect of the GREAT Intervention on Study Outcomes								
Outcomes	Intervention+		Control+		Coefficient Estimates	95% CI		p-value
	Mean	SD	Mean	SD				
Measures								
Hypothesis 1.1 (Primary)								
PAM‡	73.35	1.13	70.53	1.14	2.82	0.32	5.32	0.0271
PAM§	74.17	1.20	70.56	1.06	5.21	1.63	8.79	0.0044
Hypothesis 1.1 (Secondary)								
eHEALS‡	29.81	1.45	27.67	1.42	2.67	1.38	3.95	< .0001
eHEALS§	30.20	1.14	27.84	1.10	2.88	1.45	4.30	< .0001
DSES‡	91.89	0.86	90.81	0.87	1.09	−0.82	3.00	0.2631
DSES§	92.23	0.84	90.79	0.73	2.67	−0.09	5.43	0.0575
PICS‡	33.74	0.94	32.47	0.90	1.27	0.41	2.13	0.0038
PICS§	33.53	0.97	32.32	0.91	2.16	0.90	3.43	0.0008
Hypothesis 1.2								
IDPCS	85.06	1.24	83.49	1.25	3.18	0.01	6.35	0.0490
IDPCS§	84.55	1.18	82.02	1.05	4.97	1.58	8.36	0.0042
Hypothesis 2.1								
ASES	102.80	1.08	103.13	1.07	−0.33	−3.26	2.60	0.8251
ASES§	105.76	1.63	104.48	1.42	−0.22	−4.11	3.67	0.9130
Self-reported adherence	89.33	1.09	89.90	1.09	−0.56	−3.44	2.32	0.7014
Self-reported adherence§	90.10	1.27	89.84	1.11	−0.91	−5.21	3.40	0.6791
Undetectable viral load	87%	3.1%	86%	3.1%	0.00	−0.06	0.07	0.9113
Undetectable	89%	3.21%	87%	2.91%	0.02	−0.05	0.08	0.6172

Copyright© 2018 The University of Rochester. All Rights Reserved.

Disclaimer:

The [views, statements, opinions] presented in this report are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

Acknowledgement:

Research reported in this report was [partially] funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Award (AD-1306-03104). Further information available at: <https://www.pcori.org/research-results/2013/helping-people-living-hiv-learn-skills-manage-their-care>