The **DREAMS Toolkit** for Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Individuals

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Abstract

The DREAMS program was conceived to address low participation by older adults, particularly those who are underserved, in research. Barriers to research participation include distrust, historical mistreatment, stringent trial inclusion criteria, and health literacy. However, these barriers are not faced by older adults exclusively. Other groups find similar problems. With the DREAMS program, a two-part educational intervention, we attempt to address low participation rates in research. DREAMS is appropriate for various ages, ethnic/racial groups and socioeconomic strata. Part 1, an 8-session health seminar, covers topics related to ongoing local research. Part 2, a training course covering the research process, aims to build a cadre of participant advocates and peer recruit networks. This toolkit disseminates the DREAMS model and goals to 1) identify barriers and facilitators to implementing DREAMS, 2) implement Part I of the DREAMS program and assess it for feasibility and knowledge regarding clinical research and 3) develop and implement Part II of DREAMS to engage diverse individuals as research advocates within unique communities. We describe the materials and steps needed to effectively implement our health education and research advocacy training program for diverse individuals. We identify considerations for recruitment and education of individuals from various SES groups, health literacy levels, and racial/ethnic backgrounds. DREAMS is flexible in design, curricular content, and course implementation to best fit the needs of a given community and/or academic setting. The toolkit may serve as a general structure for course building and evaluation.

Background of the DREAMS program

The DREAMS program was originally conceived to address low participation by older adults in research. Nationwide, older adults rarely have the opportunity to engage meaningfully in research development or dissemination, although life expectancy is rapidly increasing in most developed countries, with a 30-year average increase during the 20th century (Christensen, Dobhhammer, Rau, & Vaupel, 2009). Older adults need to maintain an active role in their health care (Leach & Schoenberg, 2008), which can be accomplished by better understanding aging processes. Such understanding can only be gained via effective research. The rapidly expanding older population demands inclusive and robust patient centered outcomes research (PCOR) and comparative effectiveness research (CER) that supports patient-centered care. Older adults from low-income and racial/ethnic minority populations who are particularly at risk of adverse health outcomes related to chronic illness and multi-morbidity have historically been underrepresented in research and such underrepresentation persists (Larson, Cohn, Meyer, & Boden-Albala, 2009). Increased PCOR/CER focused on older adults will allow researchers and clinicians to gain a more robust body of knowledge concerning needs and quality care for an aging US population.

However, barriers to research participation include: distrust of the research community and difficulties with access, interpersonal communication barriers between participants and researchers (Larson et al., 2009), ageism, historical mistreatment in biomedical research contexts, stringent trial inclusion and exclusion criteria (e.g., exclusions based on multimorbidity), health disparities (e.g., cerebrovascular and cardiovascular disease affecting minorities disproportionately) (Stewart et al., 2007), consent challenges for older adults (e.g., related to cognitive impairment, or to health literacy), language issues, and reduced voluntary consent rates amongst African Americans (Glickman et al., 2008). These barriers and challenges are not faced by older adults exclusively. Other groups find similar
problems. With the development of the DREAMS program we have attempted to address older adults’ low participation rates in research, particularly among underserved populations. Our strategy has included education to increase understanding of and trust in the research process. We believe this strategy and the program details that we describe herein will also be appropriate for other populations of varying ages, and demographics. Below we describe our solution, the DREAMS program.

A Solution

The DREAMS Program, (the acronym is derived from the title of the project, Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors) a two-part educational intervention focused on diverse, underrepresented older adults, is intended to 1) build trust and rapport between older adults and researchers; 2) provide a pool of interested, educated applicants for the crucial role of patient research advocate in PCOR; and 3) increase opportunities for diverse seniors to influence, participate in and collaborate in all phases of the research process.

Part I of DREAMS is designed as an 8-week speaker series co-presented by clinical investigators and health professions students from interprofessional training institutions such as schools of medicine, nursing, and allied health. Part I educates seniors about current translational and clinical aging research related to various medical disciplines and is moderated by research coordinators and, graduate and undergraduate student volunteers. The course aims to improve older adults’ knowledge of ongoing research and of healthy-aging principles through engaging lectures and group discussion. Using learning strategies based on the latest research in cognitive psychology, participants break into small groups after hearing a lecture in order to recall and discuss the presented information. Each small group is moderated by a student volunteer, health professions student speaker, or faculty speaker. In addition to reinforcing newly learned information, these interactions help identify older adults with interest in and potential to be trained as patient advocates. Those seniors wishing to participate in advocacy training will form a group called “the DREAMS Team,” in Part II of the DREAMS program.

Part II of the educational intervention (the DREAMS Team) provides older adult trainees in-depth information on scientific research design, regulations, implementation, and dissemination, and defines the patient advocate role. The DREAMS Team is composed of participants who indicate their commitment to receiving training in patient advocacy through participation in Part I, and are selected based on recommendations of research staff and senior living community staff. The goal of the DREAMS Team is to empower these individuals so they can advocate for older persons in clinical scientific research while also advertising and recruiting for aging research projects within their communities.

As a result of participation in the DREAMS program, the following important benefits may be achieved for the involved older adults:

1. Increased knowledge of clinical research opportunities and research processes, impact, or outcomes on future clinical practice.
2. Increased likelihood of participating in clinical research following DREAMS participation.
3. Positive change in attitude toward research and participation.
Toolkit organization

The toolkit is organized by three overarching goals:

1) Identify barriers and facilitators to implementing DREAMS.
2) Develop and implement Part I of the DREAMS program and assess it for feasibility/acceptability and knowledge regarding clinical research.
3) Develop and implement Part II of DREAMS to engage diverse older adults as research advocates within their communities.

These goals and the corresponding steps to achieve them are outlined in the following pages. Materials that will be helpful for achieving the goals are found in the “Materials” section at the end of this document. We provide information that is flexible so that your DREAMS program’s design, curricular content, and course implementation can best fit the needs of your community and/or academic setting. The information described here should serve as a guide and provides general structure for course building and evaluation.

Assembling Your Team

Community/Agency Partners

Community partners will help you identify and recruit participants for your DREAMS program. First, identify communities or agencies (e.g., societies, governmental or industry) with mutual interests that will synergize with your own. For example, for our DREAMS program, we reached out to several local senior living communities’ program coordinators and directors to ask them for support of the project (Materials 1.1-1.3). Do research to find out which community partners have goals similar to yours and be thorough. You can learn a lot from an online search. Attend community events that serve your populations’ needs and talk to as many people as possible. Tell them about your plans. Try to facilitate connections with individuals that hold regular meetings. Ask for an invitation to a meeting of directors, coordinators and/or staff where you can present your ideas and gain some feedback. Visit the communities and present information about your program. You’re creating something from the ground up and may not have a fully realized plan in your mind – but enthusiasm about your goals and obvious commitment to accomplishing these goals will go a long way. Don’t hesitate to call or email an individual who you think could help your project. Quite often, one connection will lead to one or more. Think broadly. Table 1 illustrates examples of the wide variety of communities and social networks with which you may want to engage.
"Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors" (DREAMS)

Table 1. Description of Community-Based Partners

<table>
<thead>
<tr>
<th>XXXX Housing Authority</th>
<th>XXXX Resources, Inc.</th>
<th>XXXX Place</th>
<th>XXXX Towers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent and Assisted Living community; private community; predominantly middle to high income White residents; Location XXX</td>
<td>Community Education &amp; Services Organization; nonprofit, volunteer led; low or no fee (dependent upon services/courses accessed); multiple races/ethnicities; multiple socioeconomic strata and income levels</td>
<td>Independent &amp; Assisted Private Living community; predominantly middle to high income White residents; Location XXX</td>
<td>Independent living; nonprofit agency; predominantly low-income African American residents; Location XXX</td>
</tr>
</tbody>
</table>

Table 1 describes some of our community-based partners, which were appropriate for an older adult focused DREAMS program; however, other appropriate venues for recruitment could include churches or recreation facilities.

Clinical/Scientific/Academic Partners

Clinical/Scientific partners can 1) provide their perspective on how to improve participation within their research programs, and 2) provide educational lectures in Part I of the DREAMS program. It may be important to have an academic or scientific partner on your team to make contacts within the scientific/clinical community. This individual can make inroads with division/departmental directors who can help facilitate relationships with clinical stakeholders with mutual interests. Simply talking to members of the clinical community (allied health, physicians, nurses, etc.) about your idea for a DREAMS program, could lead to important connections and support that you’ll need to have a successful program. (See Contacting Clinical/Scientific/Academic Partners, Materials 2.1-2.4.) Think broadly. Many clinicians in the community are interested in helping their patient population as much as possible and would love to learn of an opportunity to interact meaningfully with them in a fun setting.

Patient Stakeholder Advisers (PSA)

PSAs are absolutely crucial to the project. Patient and community input to research methods and interpretation are important to develop patient-centered care. These individuals can be involved in all aspects of your project’s development and implementation, including study idea generation, recruitment, instrument development, data collection, analysis, interpretation and dissemination. PSAs, as direct representatives of the patient population, can serve as first line ambassadors for their peers. Identify and make contact with at least two PSAs as soon as possible in program planning. As a first step, schedule in-person meetings and conference calls with them and your team to identify initial barriers and facilitators of your DREAMS program.
You may wish to recruit PSAs from an agency or organization that already has a well-organized patient and/or patient advocate population. In this way, you have ready access to older persons who are engaged and willing to commit time and effort to a given cause. Many organizations exist for specific conditions, such as Alzheimer’s disease, Parkinson’s disease, cancer, stroke, heart disease, etc. You should make contact with and request support from these organizations that have relevant interests and to help you identify a PSA. Individuals who want to be leaders within these communities can often translate their knowledge and organizational skills to the DREAMS program you’ll be creating, provided you educate them about the program’s mission and aims. Treat PSAs as core, absolutely essential members of your team. (See Sample letter of support from patient stakeholder adviser, Materials 1.4.) Again, talk to people about your ideas, and see what happens!

Student Volunteers

Partnership with academic institutions is a great avenue for recruiting student volunteers to help implement your DREAMS program. Finding students who are bright, competent and enthusiastic can be extremely beneficial to your program. Students often need a large number of hours of volunteer/research assistant experience; working with a patient population on some level is often sought out by these students, especially those with pre-health interests. You may incorporate students into the team on an informal (and sometimes formal basis) to help with a myriad of program needs, including data entry, assessment, and assistance with programmatic offerings. Both the students and members of your program will benefit from the symbiotic relationship created. For our DREAMS program, we partnered with a medical student club called “Wesley Woods Senior University,” which provides interactive health education lectures for older adults in the Atlanta community. These medical students are very enthusiastic about opportunities for presenting to lay audiences representative of their future patients. The medical students partnered with senior faculty members to present the educational lectures in DREAMS Part I. This example is one way students from universities and community colleges can become involved in your own DREAMS program.

1st GOAL:
Identify barriers and facilitators to implementing the DREAMS Educational Program

Qualitative assessments, in the form of focus groups involving local stakeholders (community members from your population of interest), can inform and assess the development, dissemination, and implementation stages of the DREAMS Educational Program. Pre-intervention focus groups and qualitative analysis help assess stakeholders’ use of and familiarity with PCOR/CER. Using these techniques, you can derive critical information about training necessary to build a diverse community familiar with PCOR’s purpose, and will be better equipped to evaluate how your community consumes and perceives health information. This approach has proven successful in other studies/settings in tailoring education to be culturally responsive, promoting optimal stakeholder-program fit and ensuring sustainability (Echt. et al., 2013; Grant et al., 2014; Mirk et al., 2013; Quest et al., 2014).

To ensure a curriculum and educational approach that is best suited to your community’s needs, interests, and literacy level, it is critical to gather information from as many diverse groups as possible.
(i.e., spanning gender, socioeconomic strata (SES), and education levels). Taking care to include groups from low socioeconomic status and low literacy/education levels is particularly important, as these groups are those which most dearly need to be included – but are least often consulted – in the conduct of clinical research. Additionally, *adequate data collection* and *analysis* are key to understanding phenomena that will inform development of appropriate course content for your learners.

As an example, before initiating Part I of DREAMS, we conducted 4 focus groups with older adults stratified into SES (as estimated by living situation and/or location). To facilitate group discussion, each group was limited to 6-12 participants. Focus groups sessions were digitally-recorded and transcribed verbatim. An expert in qualitative assessment and analysis ran the group. Core staff of DREAMS, including both of our PSAs, participated as observers and took notes during the study group. To generate questions for the older adult focus groups (Materials 3.1), we consulted with our two PSAs, who provided extremely valuable input, and certainly brought up issues that the director and co-investigators had not considered. This example highlights the importance of involving PSAs in your program. We used a thematic analysis approach to analyze the data, which involved transcription of the recordings, and coding of themes. We conducted four focus groups for older adult participants (High SES, High-Middle SES, Low-Middle SES, and Low SES), and 2 small focus groups for clinical partners (Materials 3.2).

**Recruitment strategies for your population’s participants for focus group**

Our relationship with the university has facilitated and generated means by which we distribute recruitment information and make the crucial contacts with our participant base. These include regular ‘research social’ events that happen on at least a quarterly basis. We are often invited to attend these events with our recruitment materials, but we also can ask for space/time to recruit at events as well. We do not hesitate to ask to present at support groups and educational meetings by contacting the organizers. We consult websites to determine event timing and ask in advance for the opportunity to speak. We use Institutional Review Board (IRB)-approved methods by which we can distribute flyers (Materials 3.3) and discuss our program. We needed to gain IRB approval because our IRB representative deemed it necessary based on the focus group and other questions we would be asking. Depending on your program design, you may also be required to get informed consent from participants before the start of focus groups or DREAMS courses (Materials 5.1-5.2). Be sure to check with your academic/community organization about regulations related to recruiting and involving participants in your program. Other methods of recruitment are: registries, direct visits to residences (e.g., senior living communities) to present information, and websites related to organizations of interest.

**Recruitment Strategies for clinical partners for focus group**

The academic/scientific partner within your team can help facilitate these connections. Many clinical/scientific partners will be interested in participating in such a group. The main barrier is finding time for a group of them to meet! As such, you may wish to hold two smaller (3-4 individuals) discussion groups for the scientific partners (Materials 3.2).
Summarizing findings from a pre-intervention qualitative evaluation

Document the factors that may influence your participants’ access to and knowledge of clinical research. These factors could include: their primary means of transportation, gender, marital status, and years of education. Determine descriptive statistics about the characteristics and demographics of your groups, which can contextualize the analysis of focus group transcripts. As an example of our focus group findings from our four different older SES groups, we present a schema (Figure 1) of answers to the question, “What do you think of the term, ‘clinical research?’” Figure 2 shows themes and ideas regarding barriers and facilitators to the DREAMS program and research in general that emerged from qualitative analysis of the focus groups. Briefly, almost all High, High-Middle, and Low-Middle SES participants said they were interested in participating, but predicted the program would be a hard sell to their communities due to foreseeable issues regarding lack of mobility or lack of motivation. Even high SES participants living in senior living communities may lack transportation to attend. The Low SES group participants were the most hesitant to participate in research, showed the most distrust towards researchers and clinicians, and were most skeptical of their ability to influence others.

Figure 1. Perceptions of clinical research among older adults.
Interestingly, although not surprisingly, we found that while most high, high-mid, and low-mid SES participants had participated in research themselves or knew someone close to them who had participated, no one in the low SES focus group had participated in research themselves or had friends or family who had participated.

When designing a DREAMS curriculum, care should be taken to include particularly vulnerable, often overlooked groups. Reaching out to agencies such as low-income or public housing, churches and faith-based networks, and community services for low-income adults will help with recruiting these invaluable participants in your program. Performing a qualitative assessment of the barriers and facilitators to participation in your own community will help inform your own DREAMS program so the curriculum will be culturally sensitive, community needs-specific, and optimally effective.

2nd GOAL:
Implement Part I of DREAMS, and assess feasibility and acceptability in:

- Participant satisfaction
- Attrition
- Knowledge retention on aging research and research processes
- Attitudes toward clinical research/participation
- Likelihood of participating in clinical research in the future
It is extremely important that a program like DREAMS, which aims to have diverse representation from the older adult community, has the support of several community-based partners that are geographically and demographically representative of the community with which you are engaging. We would like to reiterate that our Community Partner table (Table 1, p.7) showed several different types of community partners, ranging from senior living communities to educational and service organizations. The common thread is that these organizations and communities provide services and support to older adults. A strategy that we find to be highly successful is to build off connections that are already in place. If you have held previous events or have existing education, clinical, or other partnerships at communities, make use of your network. The director of our DREAMS program had given in person presentations previously and had involved residents from some communities in other projects. To make new connections, a letter to the director or coordinator of an organization or community explaining the idea of a DREAMS program and asking them for support is often the start to a relationship. The letter (Materials 1.1) can be followed by an in person visit, or a short presentation to the community itself. In this way, you start a new relationship and build it through continued engagement and outreach. Building on these relationships and asking for your idea to be mentioned to others is a good way to spread the word and stimulate interest.

**Recruitment Strategies for clinical partners to serve as speakers for DREAMS Part I**

Relationships with the scientific and clinical community can be facilitated by an academic partner on your team. As an example, for our DREAMS program, we were interested in recruiting clinical and/or scientific researchers to speak on various topics related to overall healthy aging and current aging research. At our university affiliation, numerous faculty conduct aging-related research and are willing to speak about their research to lay audiences. Most often, if faculty members have the time, they will agree to be a part of a community program. It’s important that faculty understand the time commitment, the content level, and know how to present information in a lay-friendly (population-specific) way. We asked faculty to partner with medical students to present the lectures. Faculty were responsible for shorter lectures, but they also needed to meet with (in person or at least by email) the student and review their presentations before they gave the talk. This meeting was a unique opportunity for faculty and students to engage in a mentoring experience; however, the faculty member needed to be apprised of this given the additional time commitment and level of engagement.

**Recruiting student speakers**

Health professions students are often eager to make presentations and talk about their medical interests to lay audiences. Not only medical students, as in our particular program, but also physical therapy, nursing, occupational therapy, etc. students could be recruited as speakers. Make contacts with local health professional schools to identify leaders of student groups who would like to partner with you to provide lectures.
Recruitment strategies for your population’s participants

The same strategies described above for focus groups can be implemented to recruit participants for your DREAMS program. You will likely need to recruit more participants for your program, depending on how many times you want to run it. We ran four Part I courses in an academic year, with 25 participants in each course. Word of mouth is an excellent way to recruit participants for your program. Ask participants who enjoy the program or the focus group to recommend the program to others. You could also create small fliers for the participants to bring back to their facilities and peer networks (Materials 4).

Part I: the DREAMS Educational Program

Part I should foster pipelines to recruitment for local studies and active research registries. The four focus groups of older adults from diverse socioeconomic strata informed Part I of the DREAMS Program by identifying potential barriers and facilitators to implementing the program and identifying needs specific to these groups (See Figures 1 and 2). For the Part I educational program, didactic educational content will be provided to your population’s participants in an accessible way. Before implementation, have your PSAs review a range of diverse health-related topics so they can provide suggestions for delivering information that individuals with no medical background can understand.

A course in Part I of the DREAMS program should consist of eight, 90-minute stimulating and engaging interactive health seminars on a range of topics (reviewed by PSAs) to diverse members of your population (see example calendar, Materials 6.1). Participants and researchers discuss the given topic, an area of scientific inquiry for a local investigator, from the perspective of health and wellness. Participants should be given a journal to record notes and reflections. Importantly, the seminar incorporates learning techniques to enhance adult learning within a highly supportive environment.

Each seminar consists of scientific information presented by two individuals who each speak approximately 25 minutes. The first speaker is a medical or allied health student who presents the general topic. Next, the class takes a 5-10 minute break with snacks. The conversations that take place during this break are paramount to program success because they will facilitate the development of relationships amongst participants, and lead to enhanced retention because of the social interaction.

The Break: Socialization and opportunity to connect with peers is a major goal of DREAMS. Offer tea, coffee and light, healthy snacks to encourage socialization before and after classes, and during the break. Escort individuals with motor impairments to and from classrooms and check to see that your room space is environmentally friendly to your population.
Next, a faculty presenter speaks about their particular research interests. Question and answer throughout is strongly encouraged. It is very important that presenters help participants feel very welcome to be inquisitive. A member of your team should be the regular Moderator, an individual who can be responsible for technical aspects of presentation and facilitate discussion between presenters and participants.

After the lecture, the participants form small groups, in which they explore the day’s topics in more depth for 20-25 minutes. The postdoctoral (or equivalent) moderator and undergraduate volunteers monitor discussion groups by asking questions about concepts introduced in the lecture (see Materials 6.2). The small groups will be based upon learning strategies (described below). Participants may be encouraged to write down what they learned in the previous hour by recalling the information together with a partner. They will be encouraged to draw inferences, create general rules, and relate the information to their prior knowledge and experiences. In the final 5-10 minutes of the seminar, the small groups will present their thoughts, ideas and impressions to the entire group.

Request all speakers to include slides showing current research participation opportunities within their respective fields. Speakers should be given guidelines for ways to adapt their presentations to accommodate hearing and vision loss that some older adults experience, or other needs present in your participant population (see Materials 2.4). Further, presentations must follow health literacy guidelines and be presented at appropriate reading levels. In our program we required that presentations and materials match 6th-8th grade reading levels, as per Emory IRB consent forms. Example guidelines for clinical research partners can be found at http://centerforhealthguidance.org/health-literacy-principles-checklist.pdf. If medical language such as ‘chemotherapy’ must be used, ask presenters to carefully define these words. Provide large-print handouts of lecture materials at every session (see example, Materials 6.4). These handouts will be greatly appreciated by your participants!

Keep in mind that you’ll be identifying Patient advocate trainees (trained in Part II) from class participation (and recommendations from faculty, and moderators), as well as interest indicated in an exit questionnaire/personal interview. Because participation is vital to identifying those who will be good patient advocate trainees, observe participants in both large and small group settings. We believe everyone should be encouraged to consider themselves as potential patient advocate trainees. Effort should be made to assure diverse representation in Part II.

Learning strategies

Employing learning strategies based on cognitive psychological research and best practices may help facilitate the information exchange between lecturers and DREAMS participants. Three important steps to learning at any age include:

**Tips for Presenters:**
- Begin your talk by introducing yourself!
- Use large font and high contrast for your powerpoint and handouts.
- Keep your bullets to the point. Pictures are great!
- Take time to thoroughly explain charts and graphs.
- Speak slowly, clearly, amplify your voice and enunciate your words!
1) Analyzing concepts in new information
2) Determining the relationships between these ideas
3) Relating the new information to prior knowledge or experience.

Learning factual knowledge consists of exposure to information through the written or verbalized word, attending to those words, encoding of these words in Long Term Memory (LTM), and later, retrieval, which is largely contingent upon the learner’s prior knowledge and learning strategies employed (Medin, Ross, & Markman, 2005). Processing information through: attention to concepts’ novelty, idea organization, putting concepts into one’s own words, activities, and discussion facilitates retention (Craik & Tulving, 1975; DeWinstanley & Bjork, 2004; Hunt & McDaniel, 1993). Distinctiveness of ideas enhances recall because discrepancies may serve to ‘jog’ the memory by activating the representation of the concept. Encourage participants to engage with the information and actively process the new ideas, with the methods previously mentioned.

*Elaboration* is the process of using strategies like summarization and questioning. Elaboration makes listening to lecture an active process (Mayer, 2003). In note-taking, summarization engages the reader to select relevant ideas, organize them into a coherent structure with linkages to subtopics, and link them to prior knowledge. A learner who actively uses prior knowledge in comprehension is more likely to retain new information (Medin et al., 2005).

During the small group/partnered session, moderators should help participants:

1) Summarize the information learned in written form (if appropriate), with a partner, in their own words.
2) Discuss what they found novel or distinctive about the information, point out what they already knew, and identify how the new information adds to their prior knowledge.
3) Generate three or more “why?” questions about the information.
4) Present the information and questions for the lecturer to the larger group – to exchange information and receive feedback and responses.

**Program Evaluation**

Our schema for Part I shows an experimental flow (see page 13) that concerns the assessment piece. You may want to administer measures of knowledge/beliefs related to research, health literacy, participation, cognition, quality of life, etc. (see Materials 6.5) to participants prior to beginning the program and immediately after. This information will provide information related to the effects of your program on a holistic basis. You should discuss with your team, clinical partners, and PSAs which aspects of function you would be most interested in learning about with respect to the effects of your program. Importantly, immediately post-program, you should administer a satisfaction questionnaire, to learn which lectures were most appreciated and to gain overall information about the program regarding what was liked, what was disliked and any recommendations (see Materials 6.6).
3rd GOAL:
Develop curriculum for Part II, and actively engage participants as community advocates in research; determine effectiveness of Part II curriculum for training/engaging community advocates in research

Part II of the educational intervention (whose members we call the DREAMS Team) provides trainees in-depth information on scientific research design, regulations, implementation, and dissemination, and defines the patient advocate’s role. The DREAMS Team should be composed of participants who have indicated their commitment to receiving training in patient advocacy through participation in Part I. You can select members based on recommendations of research staff, senior living community staff, and academic advisors, as well as interest on the part of the participant. DREAMS Team training aims to empower individuals from your population so they can advocate important research efforts within their communities. Other ways the DREAMS Team member can engage is to serve as active members on community research advisory boards, on studies as research team members for PCOR, and as members of IRBs. These positions and roles are just a few ways that DREAMS Team members can engage in the research community and the community at large.

DREAMS Team (Part II) Curriculum

The following topics are included in 8 weekly sessions for the DREAMS Team:

1. Advocates in Research Aging: Why, Who, & What?
2. The Clinical Research Process: Focus on Patient-Centered Outcomes Research
3. Ethics and Aging Research
5. Aging and Clinical Research: What’s in the Pipeline
6. Informed Consent: Understanding the Issues and Health Literacy
7. Effective Advocacy within the Clinical Research Process
8. Final Class: Hearing from the Ones in the Trenches, and Getting Started as an Advocate in Aging Research

These topics are presented by content experts. Identifying these content experts in your community could take a little sleuthing but be sure to use all the contacts with organizations, clinical partners, and community partners at hand. In particular, it will be important that the expert speakers understand that material needs to be presented at a level that the participants will understand. For example, for the Analysis lecture, our faculty member came up with a unique and fun way to explain distributions, and methods of evaluating the significance of differences between groups. He asked the class how many people had grandchildren, and how many they had. He then compared their distribution to the numbers of grandchildren past US presidents had at the time of inauguration. Without getting too much in the weeds of history, the participants enjoyed learning about numbers, ratios, and statistical differences in a relatable way. This example is just one illustrating how experts can present highly sophisticated content in a fun and informative way. This training course curriculum is heavily inspired by the Parkinson Disease foundation (PDF) Patient Advocates in Research (PAIR) program. We tailored it to the needs of the
“Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors” (DREAMS)

general older adult population and you can tailor yours to the specific needs and interests of your population of interest.

The classes in Part II take on a similar format to Part I, with lecture (and plenty of Q&A) in the first 50 minutes, a break in the middle, and small group discussion in the last 20-25 minutes. We include example small group discussion questions in Materials 6.3. You should tailor the questions you ask and the group discussion foci to your group.

Programmatic Evaluation

![Figure 4. Experimental flow through for DREAMS Part II, the DREAMS Team.](image)

As with Part I, you should continue to administer measures of function to participants to determine your program’s effectiveness. This information will lend strength to reasons to continue your program with ongoing funding. Figure 4 shows a possible timeline for evaluation. Short-term assessments could include: racial/ethnic makeup of the participants, participants’ attitudes about the program and their perceptions/knowledge regarding research process.

For DREAMS Team Members, you should also follow them for 6 months or more to see how they are engaging within the community and what measurable impact is occurring. These outcomes could include but are not limited to the following:

- a. knowledge acquisition, number of new research protocols involving diverse individuals from your population as study participants or as research team members
- b. increased member participation in studies and/or registries
- c. number of research recruitment events hosted by the DREAMS Team
- d. number of research recruitment presentations by the DREAMS Team
- e. number of new research participants recruited into research projects as result of DREAMS Team individual efforts and/or DREAMS-affiliated socials/recruitment events
- f. number of DREAMS Team members joining patient advocacy/research advisory or IRB boards
- g. blogging or writing short essays for patient journals

Opportunities to Practice the Patient Advocate Role

After the DREAMS Team members have completed training, you should regularly and often look for opportunities for DREAMS Team Members to practice the patient advocate role. In preparation for their role as community advocates in research, your DREAMS Team should meet with your project team and clinical research partners from Part I. In this meeting, the DREAMS Team member can learn specific ways they can help educate their communities regarding research opportunities at local universities and the clinical institutions (e.g., the hospital, the local VA medical center, clinics). You could help your
DREAMS Team Member organize research socials in which clinical partners could present research information. Importantly, each DREAMS Team member should have an opportunity to help host these socials, and help answer questions related to general participation in research both at the social and in the weeks following. At research events, encourage your DREAMS Team to participate as recruiters for research projects as an official liaison and/or by giving the research participant perspective to complement the scientific perspective that the PI or research staff member delivers.

The ‘formula’ for a successful patient advocacy training program does not exist, and the outcomes from these engagements are multiple. Continually engaging with your DREAMS Team Members will allow you to identify meaningful opportunities for them to actively serve in the patient advocacy role and make a difference in their community!

Expected Project Outcomes and Impact

Educational programs tailored to the needs of your population of interest can enhance function, independence, and self-efficacy. Enhanced understanding of the research process, when delivered in a lay-friendly manner designed to motivate participation, can increase research participation, particularly by underserved individuals. Preparing diverse representatives of your population to be active in PCOR is vital to enabling investigators from across the research spectrum to create projects, which will ultimately improve healthcare delivery and health outcomes for all individuals. Increased participation by informed individuals across multiple racial/ethnic and socioeconomic strata will impact the research process in meaningful ways, by allowing researchers to more accurately characterize the healthcare challenges they face, thus leading to better health outcomes as well as decreased burden and cost to healthcare systems.
References


Materials

1. Contacting community partners

1.1 Sample letter of inquiry (initial contact)

Dear X, I would like to tell you about a grant proposal that Drs. Madeleine Hackney, Molly Perkins, and I are submitting to the Patient Centered Outcomes Research Institute (PCORI). We are proposing to build an 8-week educational program for older adults about healthy aging, new research in fields relating to aging (vision, diabetes, heart disease), and how to access patient advocacy boards in clinical research.

We would really like to partner with XXX Organization so that we could recruit students from the 11 senior high rises around town. If funded, the grant would provide transportation vouchers as well as a participant stipend of up to $120 dollars per person.

Would you be willing to sign a letter of support for our proposal stating that AHA is supportive?

If so, please feel free to use the attached letter template.

Please feel free to let me know if you have any questions – we appreciate your consideration!

Best,

Rebecca

1.2 Sample follow up communication

Dear Community partner,

Our PCORI (Patient-centered outcomes research institute) grant, for which you graciously offered a letter of support on behalf of XXX communities was funded! Thank you for your support!

To remind you, the project involves the creation of the DREAMS program, which will encompass 8-week health seminars about ongoing research at Emory and ways for seniors to participate in research. There will be four 8 week courses offered in the first year (Part I), and 2, 8 week courses in the second year (Part II). Part II will be composed of ‘students’ picked from Part I, who are especially interested in becoming patient research advocates. The courses will be held at the Wesley Woods Health Center on Emory campus. I understand that transportation could be an issue for seniors who are interested in participating; however, we might be able to arrange for transport if several interested seniors from XXX decide to participate.

For initial steps- we are interested in presenting the program to XXX senior living community residents in an informative seminar, with opportunities for Q&A, and are also looking for seniors to participate in initial focus groups that we will be conducting to optimize our programmatic offerings. We would like to gauge your interest whether this would be possible.

Thank you!

Madeleine
1.3 Sample letter of support from community partners

XXXXXXX, PhD
Assistant Professor
Division of XXXXX Medicine
XXXXX University School of Medicine

August [XX], 2014
Dear Dr. XXXX,

I would like to express my enthusiasm for collaboration between the XXX Housing Authority's Senior High Rise communities and the XXX Center for Health in Aging in support of your proposed program, “Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors.”

We are aware that seniors from low-income and racial/ethnic minority populations, who often struggle with multiple chronic health issues, have been historically underrepresented in research. Additional barriers with these particular groups of senior citizens include distrust of the research community and misinformation or lack of knowledge about the research process. The XXX Housing Authority understands the importance of developing a diverse community of patients, clinicians, and researchers who are fully educated and engaged in patient centered research and clinical effectiveness research; therefore, we are enthusiastic about this partnership and the potential benefits for both our senior residents and the XXX research community.

Participation in your lecture series and the opportunity for some members of our community to be trained as patient advocates would provide a welcome wellness outlet for our residents but also allow us to identify specific needs at the local and neighborhood level, especially those of low-income and minority older adults. Having access to trained patient advocates who are also members of underrepresented groups, as well as becoming familiar with the exciting patient centered research going on in Atlanta, would go far towards breaking down barriers of distrust and misinformation that currently exist, to the benefit of the greater community we serve.

The XXX Housing Authority fully supports this program and we look forward to partnering with the XXX Center for Health in Aging for the benefit of our senior residents.

Sincerely,

[TITLE]

XXX Housing Authority
1.4 Sample letter of support from patient stakeholder adviser

Madeleine Hackney, PhD
Assistant Professor
Division of General Medicine and Geriatrics
Emory University School of Medicine
1841 Clifton Road, NE, 5th floor
Atlanta, Georgia 30328

September 25, 2014

Dear Dr. Hackney,

As a trained patient advocate through the Parkinson’s Advocates in Research (PAIR) Program, I was excited to learn about your proposed project, “Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors.” I am writing to offer my support for this project as a community advisor and patient partner. I look forward to working together to expand the number of patient advocates here in the Atlanta area.

The PAIR Program is sponsored by the Parkinson’s Disease Foundation and I am one of over 200 participants in the US and Canada currently in partnership with over 500 research professionals and support groups to bring better treatments to market faster. In order to participate in this network, I completed training at the PAIR Learning Institute, focusing on the science of Parkinson’s disease, the process that brings new treatments to market, and the development of leadership/advocacy skills to interact effectively with the research community. I know that my skills will benefit your program.

As a patient partner for your project, I will attend bimonthly research team meetings and provide input and feedback on developing study instruments and project materials. I will be available to help with data collection and analysis. I can also assist with participant recruitment. In exchange for these services, I understand that I will receive a small stipend.

Becoming involved in patient-centered outcomes research has shown me how valuable PCOR is to the research community. More seniors need to become involved, in all aspects of the research, for the greater good of our health as a community. I would welcome the chance to act as a community advisor for your project, thereby encouraging diverse seniors to take an active part in the future of medicine.

Sincerely,

XXX [Signature]

XXX
CEO & Founder
XXX Corporation
[Phone]
[Email]
2. Contacting Clinical/Scientific/Academic Partners

2.1 Invitation to participate in focus group

Dear Dr. XXX,

I hope you are well. I am writing to share the very good news that the proposal that my colleagues, Dr. Molly Perkins and Rebecca Dillard of the Center for Health in Aging, submitted for the Eugene Washington PCORI Engagement Award was funded! We are immensely grateful to you for sharing your support for this proposal.

To remind you, the title of our project is "Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors", or DREAMS. We aim to connect with SOM research groups engaging in work related to aging/older adults, but who may need support to develop patient centered outcomes research (PCOR) focused on the aging community.

We have asked our partners to help determine appropriate faculty within their division who could, over a year, deliver one to four 1-hour lectures that focus on ongoing or upcoming research projects and their relationship to healthy aging. These lay person-friendly lectures will be delivered to diverse seniors from the Atlanta community and take place at Wesley Woods Health Center.

As an initial step, we would like to invite you to participate in a focus group of our clinical partners, led by Dr. Molly Perkins, to gather information about barriers and facilitators to engaging seniors in research. We will try to arrange this meeting at a mutually convenient location and time for all partners.

More information follows about the goals of the project:

With a two-part educational intervention for diverse, underrepresented older adults, we aim to 1) build trust and rapport between older adults and researchers, 2) provide a pool of interested, educated applicants for the crucial role of patient research advocate in PCOR, and 3) increase opportunity for diverse seniors to exert influence, participate and collaborate in all phases of the research process.

Part I, an 8-week speaker series presented four times by local investigators and staff in year 1, will educate seniors about current translational and clinical aging research. Small group discussion and recall will help identify older adults with interest in and potential to be trained as patient advocates. These trainees will be invited to participate in Part II, a second course which will provide the trainees in-depth information on scientific research design, implementation, and dissemination, as well as characterize the patient advocate role.

Again, we are sincerely appreciative for your support and involvement in the project. We hope you will be able to participate in the focus group. Please let us know if there are any barriers to doing so, otherwise, we will have someone contact you shortly to schedule this meeting.

Thank you!

Madeleine
2.2 Seeking speakers for DREAMS Part I

Dear Dr. XXX,

We are grateful for your support of the DREAMS project, a two part educational intervention for older adults funded with a Eugene Washington Award from PCORI (PI, Madeleine E. Hackney, co-Is, Molly Perkins and Rebecca Dillard). (Please see the thread below which details more about the project).

We are now seeking faculty speakers (clinical Aging researchers) for the courses, which are intended for inquisitive older adults. We would appreciate your serving as a speaker - or please suggest the names and contact information of researchers within your division or research team who could deliver 1-4 short lectures (over the academic year) focusing on their research projects related to aging.

Starting in October, the DREAMS project will host two 8-week courses (Courses A&B) accommodating 20 seniors each. Each class in the course will cover a unique topic related to healthy aging currently researched at Emory SOM. We are also involving an Emory medical student club to offer the lectures.

Commitment for faculty: ~ 1 hour per course. Each class will meet 1.5 hours. A medical student will present the research topic on a basic level in the first half hour. Next the faculty member will present their specific research interests for ~ 20 minutes. The final half hour involves small group and partnered learning in which the faculty member, medical student and moderators discuss the topic in greater depth with the older adults. Such practices have led to greater learning retention.

We ask that the faculty member a) prepare a 20 minute lecture, with slides and handouts for a lay person audience, and b) provide input to the medical student on their presentation’s content. The medical student will contact the faculty member for this input.

The courses will be offered four times this academic year: Course A, B, C and D. Faculty are encouraged to participate in all four courses, but can suggest an alternate member of their research team to present in case of schedule conflicts.

Where and When: All classes meet 10:30am-12pm at the Wesley Woods Health Center 5th floor conference room.
Course A meets Mondays, beginning October 5. We need speakers for 10/12, 10/19, 10/26, 11/2, 11/9, 11/16 and 11/23.
Course B meets Thursdays, beginning October 22. We need speakers for 10/22, 10/29, 11/5, 11/12, 11/19, skip T’giving, 12/3, 12/10, and 12/17.
Courses C and D will take place Jan-Mar 2016.

Please do not hesitate to contact us if you have any questions.

Many thanks for your support,

Madeleine, Molly and Rebecca
2.3 Follow up seeking speakers for DREAMS Part I

Dear Dr. XXX,

I'm following up with you regarding my PCORI-funded project, DREAMS. We seek speakers for our 2 courses for older adults this fall. Could you OR a research team member/fellow provide a 20 minute lecture about your research interests on one of the following dates? (See thread below for more details.)

All classes meet 10:30 to 12pm in the WWHC 5th floor conference room.

Course A meets Mondays, beginning October 5. We need speakers for 10/26, 11/9, 11/16, 11/23.
Course B meets Thursdays, beginning October 22. We need speakers for 11/5, 11/12, 11/19, 12/3, 12/17.

Many thanks for your support of this project!

Madeleine

2.4 Sample reminder letter for faculty speakers

Dear Dr. XXX,

We greatly thank you for agreeing to present for the PCORI-funded DREAMS project (PI: Madeleine Hackney, Co-Is: Molly Perkins and Rebecca Dillard) for older adults. **see below for more information about the goals of the project

**Date/Time:** Thursday, March 17, 2016, **10:30AM-12PM**

*Please arrive by 10:15 am* to allow at least 15 minutes prep time for setting up your presentation. The students come early and are prepared to start (and end) ON TIME!

**Location:** 5th floor conference room, Wesley Woods Health Center on Emory Campus: 1841 Clifton Rd NE, Atlanta, GA 30329.

**Who is your audience?** Adults aged 55+ from diverse backgrounds. Some may have hearing and visual loss.

**Class format:** The medical student assigned to you will present the research topic on a basic level in the first half hour. (He/she should be contacting you soon.) Then there will be a 10 minute break for coffee and snacks. Next you will present your specific research interests for ~20-25 minutes. The final half hour will involve small group learning in which you, your medical student and moderators discuss the topic in greater depth with the older adults.

*Please print 30 handouts of your slides* - these should be printed 2 slides to a page, double sided. If you would like [project coordinator] to print the handouts, please let us know ASAP and send your slides at least 1 full business day before the class.
“Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors” (DREAMS)

* If you are running late on the day of your lecture, please call [project coordinator] immediately at my cell: xxx-xxx-xxxx.

Please also:

- Begin your talk by introducing yourself, your research interests, why you were drawn to health/medicine, etc.
- Use large font and high contrast for your powerpoint and handouts.
- Keep your bullets to the point. Pictures are great! Take time to thoroughly explain charts and graphs.
- Speak slowly, clearly, amplify your voice and enunciate your words, because students may be hard of hearing.
- Contact XXX with any questions about preparing your lecture.

**Goals of the DREAMS program:**

With a two-part educational intervention for diverse, underrepresented older adults, we aim to 1) build trust and rapport between older adults and researchers, 2) provide a pool of interested, educated applicants for the crucial role of patient research advocate in PCOR, and 3) increase opportunity for diverse seniors to exert influence, participate and collaborate in all phases of the research process.

Part I, an 8-week speaker series presented four times by local investigators will educate seniors about current translational and clinical aging research. Small group discussion and recall will help identify older adults with interest in and potential to be trained as patient advocates. These trainees will be invited to participate in Part II, a course which will provide the trainees in-depth information on scientific research design, implementation, and dissemination, and characterize the patient advocate role.

We are excited about your participation and confident that your important presentation will be greatly appreciated by these inquisitive older adults from the community.

Please confirm that you received this information and don't hesitate to contact us with questions.

Thank you!
3. Focus Group Materials

3.1 Focus groups with Diverse Community-Dwelling Older Adults

Interviewer: Thank you so much for agreeing to participate in this focus group. We are developing an educational intervention to promote older adults’ participation in clinical research and would like to ask you some questions that will inform development of this project. We will use a digital recorder and will ask you to speak one person at a time. This will help us hear what you say more clearly. We want to hear from all of you. Does anyone have any questions? Okay, well let’s get started.

1. I’d like to start by going around the circle and asking each of you to tell me what you think of when you hear the term, “clinical research.”

   **Probes:**
   - *What do you think scientists do when they do research?*
   - *Why does research tell us? What purpose do you think research serves? Why do you think we do human research?*
   - *What are your feelings toward doctors, nurses, and other types of researchers who do clinical research? Probe for factors that have contributed to these attitudes*

2. Have you, a family member, or someone else you know ever participated in research?

   **Probes:**
   - *What was that experience like?*
   - *Probe for both positive and potentially negative experiences.*
   - *Probe for factors that influenced participants’ experiences.*

3. Do you know of any health conditions that you or your family have or that you know about that you would prefer that future generations (e.g., your grandchildren and great grandchildren) did not need to worry about?

   **Probes:**
   - *Do you see research as a way to improve health of future generations?*
   - *Probe for positive as well as potentially negative attitudes.*

4. Give Overview of project goals (lay summary) and then ask: What are your initial impressions about this project?

   **Probes:**
   - *If we came to promote this project at your community, what would you want to know? What questions would you have? What would you need to know?*
   - *How do you like to learn? (e.g., PowerPoint, demonstrations, small group, etc.)?*
   - *Would you be willing to participate in this project? Why or why not?*
   - *Probe for factors that would promote participation and potentially limit participation.*
   - *Probe for recommendations participants have for promoting participation.*

5. Based on our discussion today, does anyone have any final thoughts? Recommendations?
3.2 Focus groups with Scientific Partners

Interviewer: Thank you so much for agreeing to participate in this focus group. As you know, we are developing an educational intervention to promote older adults’ participation in clinical research and would like to ask you some questions that will inform development of this project.

We will use a digital recorder and will ask you to speak one person at a time. This will help us hear what you say more clearly. We want to hear from all of you. Does anyone have any questions? Okay, well let’s get started.

1. Give overview of project goals (lay summary) and then ask: What are your initial impressions regarding this project?

Probes:

- Probe for both perceived barriers and facilitators.
- Probe for specific attitudes about Part 1.
- Probe for specific attitudes about Part 2.

2. Present a summary of findings from the focus groups with older adults and then ask the scientific partners for their initial reaction/impressions.

Probes:

- If barriers were identified, probe for recommendations for addressing.
- Probe for any perceived changes that might need to be made to the project.

3. What are the barriers you see for recruiting older adults into your research?

Probes:

- Do you feel you have adequate resources to recruit older adults in your research?
- Probe for perceived barriers (e.g., language issues, transportation, cultural barriers, cognitive issues) and facilitators to recruitment.

4. Based on our proposed project, what from your perspective do older adults need to know about the research process? Probe as needed/indicated.

5. Based on our discussion today, does anyone have any final thoughts? Recommendations?
BE A PART OF THE DREAM!

Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors

✓ Do you want to improve the impact that research has on older adults’ healthcare in a meaningful way?
✓ Do you want to improve healthcare for older adults?

If you answered YES, we welcome you to participate in an Emory study to learn what older adults think of clinical research for health and wellness.

What is my commitment?
* Participate in a focus group to help Emory researchers understand what older adults think of clinical and health services research. * Tell them what health and wellness topics are most important to you. * Help them figure out the best ways to reach out to other older adults, to deliver health education and to follow up to make sure people remain interested.

When and Where? July 21, from 2 to 4 pm.

* Refreshments will be provided. Space is limited to the first 10 participants.

For information, please call:
XXX at [Phone #]
BE A PART OF THE DREAM!

Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors

✓ Do you want to receive health education from top doctors at Emory University?
✓ Do you want to impact research in meaningful ways?
✓ Do you want to improve healthcare for mature adults?
   If you answered YES, we welcome you to participate in our research study evaluating a health education series.

What is my commitment?
Participate in assessments of your cognition, mobility and psychosocial health before, immediately after and 8 weeks after an 8 week health education seminar meeting weekly. Classes are 1.5-hour long and provided by Emory faculty!

Where?
Wesley Woods Health Center, 5th floor
1841 Clifton Rd. Atlanta, GA 30329

Participants will receive compensation for their time.

For information, please call:
XXX at [Phone #]
5. Obtaining Consent

5.1 Sample Informed Consent Document: Older Adult Focus Group

You Are Being Asked to Be in a Research Study

What Is a Research Study?

The main purpose of research studies is to gain knowledge. This knowledge may be used to help others. Research studies are not intended to benefit you directly, though some might.

Do I Have to Do This?

No. Being in this study is entirely your choice. If you decide to join this study, you can change your mind later on and withdraw from the research study.

Taking part in a study is separate from medical care. The decision to join or not join the research study will not affect your status as a patient.

What Is This Document?

This form is an informed consent document. It will describe the study risks, procedures, and any costs to you.

This form is also a HIPAA Authorization document. It will describe how your health information will be used and by whom.

Signing this form indicates you are willing to take part in the study and allow your health information to be used.

What Should I Do Next?

1. Read this form, or have it read to you.
2. Make sure the study doctor or study staff explains the study to you.
3. Ask questions (e.g., time commitment, unfamiliar words, specific procedures, etc.)
4. If there will be medical treatment, know which parts are research and which are standard care.
5. Take time to consider this, and talk about it with your family and friends.
“Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors” (DREAMS)

Emory University
Consent to be a Research Subject / HIPAA Authorization

Title: Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors
Principal Investigator: Madeleine E. Hackney, PhD

Sponsor: Patient Centered Outcomes Research Institute (PCORI)

Introduction
You are being asked to be in a medical research study. This form is designed to tell you everything you need to think about before you decide if you want to be a part of the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.**
The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

Before making your decision:
- Please carefully read this form or have it read to you
- Please listen to the study doctor or study staff explain the study to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. You may wish to discuss your decision with family or friends. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you. By signing this form you will not give up any legal rights.

What is the purpose of this study?
The purpose of this study is to determine the barriers and facilitators to older adults participating in research. We also aim to determine the effects of an interactive educational seminar on cognition, quality of life, and willingness to engage as a research participant. We aim to prepare older adults to engage in Patient Centered Outcome Research (PCOR) as educated research participants and research advisory board advocates across disciplines. We will educate older adults about the value of research, teach them the importance of their participation and provide them with opportunities to participate in PCOR.

What will I be asked to do?
You will be asked to take part in one or more of the following activities:

- A focus group for older adults, meeting one instance, to discuss attitudes related to the research process. The focus group will be audio tape recorded.
- A 1.5 hour health education seminar meeting once per week for 8 weeks.

At the assessment immediately after the health seminar you may be asked to participate in a focus group participation, which will be audio tape recorded.
  - If you attend the health seminar, you may be asked to take part in the DREAMS Team, a group of older adults who will be trained as research advocates in 8, 1.5 hour sessions.
over 8 weeks. These individuals will learn extensively about the research process and will serve as advocates within their communities for research participation. If you become part of the DREAMS Team, you will be asked to participate in assessments of mobility, cognition and psychosocial health before, immediately after and 8 weeks after the DREAMS Team program.

**Who owns my study information and samples?**
If you join this study, you will be donating your study information. If you withdraw from the study, data that were already collected may be still be used for this study.

**What are the possible risks and discomforts?**
There may be side effects from the study intervention that are not known at this time. The most common risks and discomforts expected in this study are boredom, impatience or fatigue with the assessments.
There is the risk of breach of confidentiality. If you participate in the focus group, there is also the risk of breach of confidentiality. Everyone will be asked not to discuss the information shared in the focus group with others, but this cannot be guaranteed because the other participants are not required by law to maintain confidentiality.
There are no other foreseeable risks.
It is possible that the researchers will learn something new during the study about the risks of being in it. If this happens, they will tell you about it. Then you can decide if you want to continue to be in this study or not. You may be asked to sign a new consent form that includes the new information if you decide to stay in the study.

**Will I benefit directly from the study?**
This study may benefit you through the chance to learn more about health and wellness. The study results may be used to help others in the future.

**Will I be compensated for my time and effort?**
If you participate in the Health Seminar, you will get $20 for the first completed study visit, to compensate you for your time and effort. You will be compensated $40 if you complete the Health Education Seminar and participate in the assessment immediately after the last class of the program. If you participate in the assessment 8 weeks after completion of the health seminar, you will be compensated $60. You will get $120 total, if you complete all study visits.

If you are asked to be part of the DREAMS Team, you will get $20 for the first completed study visit, to compensate you for your time and effort. You will be compensated $40 if you complete the Health Education Seminar and participate in the assessment immediately after the last class of the program. If you participate in the assessment 8 weeks after completion of the health seminar, you will be compensated $60.

If you do not finish the study, we will compensate you for the visits you have completed. You may be asked to fill out a tax form, including your Social Security or Taxpayer Identification Number, to be reimbursed, depending on the amount and method of payment. Some payment methods involve mail coming to your house, which may be seen by others in your household. You can decline payment if you are concerned about confidentiality, or you can talk to the study team to see if there are other payment options.
What are my other options?
If you decide not to enter this study, there is care available to you outside of this research study.

How will you protect my private information that you collect in this study?
Emory will keep any research records that it creates private to the extent that this is required to do so by law. Whenever possible, a study number, rather than your name, will be used on study records. Your name and other identifying information will not appear when we present or publish the study results.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents.

Medical Record
If you have been an Emory Healthcare patient before, then you already have an Emory Healthcare medical record. If you have never been an Emory Healthcare patient, you do not have one.

The results of some study tests and procedures will be used only for research purposes and will not be placed in your medical record. For this study, those items include results of mobility, cognitive and psychosocial tests.

Tests and procedures done at non-Emory places may not become part of your Emory medical record. Also, if you decide to be in this study, it is up to you to let your other health providers know.

Costs
There will be no costs to you for participating in this study, other than basic expenses like transportation. You will not be charged for any of the research activities.

Withdrawal from the Study
You have the right to leave a study at any time without penalty. The researchers also have the right to stop your participation in this study without your consent for any reason, especially if they believe it is in your best interest or if you were to object to any future changes that may be made in the study plan.

Authorization to Use and Disclose Protected Health Information

The privacy of your health information is important to us. We call your health information that identifies you, your “protected health information” or “PHI.” To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act and regulations (HIPAA). We refer to all of these laws as the “Privacy Rules.” Here, we let you know how we will use and disclose your PHI for the study.

PHI that Will be Used/Released:
- Medical information about you including your medical history and present/past medications.
- Results of exams, procedures and tests you have before and during the study.
- Photographs, video and audio recordings
**Purposes for Which Your PHI Will be Used/Disclosed:**
We will use and share your PHI for the conduct and oversight of the research study. We will use and share your PHI to provide you with study related treatment and for payment for such treatment. We will also use and share your PHI to conduct normal business operations. We may share your PHI with other people and places that help us conduct or carry out the study, such as laboratories, data management centers, data monitors, contract research organizations, Institutional Review Boards (IRBs) and other study sites. If you leave the study, we may use your PHI to determine your health, vital status or contact information.

**Use and Disclosure of Your Information That is Required by Law:**
We will use and disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or abuse of older or disabled adults. We will also comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

**Authorization to Use PHI is Required to Participate:**
By signing this form, you give us permission to use and share your PHI as described in this document. You do not have to sign this form to authorize the use and disclosure of your PHI. If you do not sign this form, then you may not participate in the research study or receive research-related treatment. You may still receive non-research related treatment.

**People Who will Use/Disclose Your PHI:**
The following people and groups will use and disclose your PHI in connection with the research study:

- The Principal Investigator and the research staff will use and disclose your PHI to conduct the study and give you study related treatment.
- Emory may use and disclose your PHI to get payment for study related treatment and to run normal business operations.
- The Principal Investigator and research staff will share your PHI with other people and groups to help conduct the study or to provide oversight for the study.
- PCORI is the Sponsor of the study. The Sponsor may use and disclose your PHI to make sure the research is done correctly and to collect and analyze the results of the research. The Sponsor may disclose your PHI to other people and groups like study monitors to help conduct the study or to provide oversight for the study.
- The following people and groups will use your PHI to make sure the research is done correctly and safely:
  - Emory offices that are part of the Human Research Participant Protection Program and those that are involved in study administration and billing. These include the Emory IRB, the Emory Research and Healthcare Compliance Offices, and the Emory Office for Clinical Research.
  - Public health agencies.
  - Research monitors and reviewer.
  - Accreditation agencies.

**Expiration of Your Authorization**
Your PHI will be used until the end of record keeping requirements.
Revoking Your Authorization
If you sign this form, at any time later you may revoke (take back) your permission to use your information. If you want to do this, you must contact the study team at:

Madeleine E. Hackney, PhD
XXXX Clairmont Rd.
Decatur, GA 30033
XXX-XXX-XXXX

At that point, the researchers would not collect any more of your PHI. But they may use or disclose the information you already gave them so they can follow the law, protect your safety, or make sure that the study was done properly and the data is correct. If you revoke your authorization you will not be able to stay in the study.

Other Items You Should Know about Your Privacy
Not all people and entities are covered by the Privacy Rules. HIPAA only applies to health care providers, health care payers, and health care clearinghouses. If we disclose your information to people who are not covered by the Privacy Rules, including HIPAA, then your information won’t be protected by the Privacy Rules. People who do not have to follow the Privacy rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them.

To maintain the integrity of this research study, you generally will not have access to your PHI related to this research until the study is complete. When the study ends, and at your request, you generally will have access to your PHI that we maintain in a designated record set. A designated record set is data that includes medical information or billing records that your health care providers use to make decisions about you. If it is necessary for your health care, your health information will be provided to your doctor.

We may remove identifying information from your PHI. Once we do this, the remaining information will not be subject to the Privacy Rules. Information without identifiers may be used or disclosed with other people or organizations for purposes besides this study.
**Contact Information**

Dr. Madeleine Hackney at 404-321-xxxx, ext 5xxx:
- if you have any questions about this study or your part in it,
- if you feel you have had a research-related injury or a bad reaction to the study drug, or
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:
- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

**Consent and Authorization**

Please print your name and sign below if you agree to be in this study. By signing this consent and authorization form, you will not give up any of your legal rights. We will give you a copy of the signed consent to keep.

__________________________________________________________
Name of Subject

__________________________________________________________  ________________
Signature of Subject                     Date

__________________________________________________________
Name of Person Conducting Informed Consent Discussion

__________________________________________________________  ________________
Signature of Person Conducting Informed Consent Discussion                     Date
5.2 Sample Informed Consent Document: Scientific Partners Focus Group

You Are Being Asked to Be in a Research Study

**What Is a Research Study?**

The main purpose of research studies is to gain knowledge. This knowledge may be used to help others. Research studies are not intended to benefit you directly, though some might.

**Do I Have to Do This?**

No. Being in this study is entirely your choice. If you decide to join this study, you can change your mind later on and withdraw from the research study.

Taking part in a study is separate from medical care. The decision to join or not join the research study will not affect your status as a patient.

**What Is This Document?**

This form is an informed consent document. It will describe the study risks, procedures, and any costs to you.

This form is also a HIPAA Authorization document. It will describe how your health information will be used and by whom.

Signing this form indicates you are willing to take part in the study and allow your health information to be used.

**What Should I Do Next?**

6. Read this form, or have it read to you.
7. Make sure the study doctor or study staff explains the study to you.
8. Ask questions (e.g., time commitment, unfamiliar words, specific procedures, etc.)
9. If there will be medical treatment, know which parts are research and which are standard care.
10. Take time to consider this, and talk about it with your family and friends.
Title: Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors

Principal Investigator: Madeleine E. Hackney, PhD

Sponsor: Patient Centered Outcomes Research Institute (PCORI)

Introduction
You are being asked to be in a medical research study. This form is designed to tell you everything you need to think about before you decide if you want to be a part of the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

Before making your decision:
- Please carefully read this form or have it read to you
- Please listen to the study doctor or study staff explain the study to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. You may wish to discuss your decision with family or friends. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you. By signing this form you will not give up any legal rights.

What is the purpose of this study?
The purpose of this study is to determine the barriers and facilitators to older adults participating in research. We also aim to determine the effects of an interactive educational seminar on cognition, quality of life, and willingness to engage as a research participant. We aim to prepare older adults to engage in Patient Centered Outcome Research (PCOR) as educated research participants and research advisory board advocates across disciplines. We will educate older adults about the value of research, teach them the importance of their participation and provide them with opportunities to participate in PCOR.

What will I be asked to do?
You will be asked to take part in a focus group. This group will meet for 1 to 1.5 hours and will include questions related to perceived barriers to recruiting older adults for research studies. The focus group will be digitally recorded.
Who owns my study information and samples?
If you join this study, you will be donating your study information. If you withdraw from the study, data that were already collected may be still be used for this study.

What are the possible risks and discomforts?

There may be side effects from the study intervention that are not known at this time.
The most common risks and discomforts expected in this study are boredom with the focus group.
There is the risk of breach of confidentiality.
If you participate in the focus group, there is also the risk of breach of confidentiality. Everyone will be asked not to discuss the information shared in the focus group with others, but this cannot be guaranteed because the other participants are not required by law to maintain confidentiality.
There are no other foreseeable risks.
It is possible that the researchers will learn something new during the study about the risks of being in it. If this happens, they will tell you about it. Then you can decide if you want to continue to be in this study or not. You may be asked to sign a new consent form that includes the new information if you decide to stay in the study.

Will I benefit directly from the study?
This study may benefit you through the chance to express your views about research. This study may help future researchers understand barriers to recruiting older adults and come up with strategies to facilitate recruitment.

Will I be compensated for my time and effort?
You will not be compensated for participating.

What are my other options?
You may decide not to enter this study.

How will you protect my private information that you collect in this study?
Emory will keep any research records that it creates private to the extent that this is required to do so by law. Whenever possible, a study number, rather than your name, will be used on study records. Your name and other identifying information will not appear when we present or publish the study results.

Study records can be opened by court order. They also may be provided in response to a subpoena or a request for the production of documents.

Costs
There will be no costs to you for participating in this study, other than basic expenses like transportation. You will not be charged for any of the research activities.

Withdrawal from the Study
You have the right to leave a study at any time without penalty. The researchers also have the right to stop your participation in this study without your consent for any reason, especially if they believe it is in your best interest or if you were to object to any future changes that may be made in the study plan.
Contact Information
Dr. Madeleine Hackney at 404-321-xxxx, ext 5xxx:
  • if you have any questions about this study or your part in it,
  • if you feel you have had a research-related injury or a bad reaction to the study drug, or
  • if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:
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  • if you have questions, concerns or complaints about the research.
  • You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Consent and Authorization

Please print your name and sign below if you agree to be in this study. By signing this consent and authorization form, you will not give up any of your legal rights. We will give you a copy of the signed consent to keep.

__________________________________________________________
Name of Subject

__________________________________________________________
Signature of Subject  Date

__________________________________________________________
Name of Person Conducting Informed Consent Discussion

__________________________________________________________
Signature of Person Conducting Informed Consent Discussion  Date
“Developing a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors” (DREAMS)

6. Course Materials and Evaluations

6.1 Part I Sample Course Calendar/Topics

Welcome to the DREAMS Program!

DREAMS Courses A and B meet from 10:30 AM-12:00 PM in the 5th floor conference room of the Wesley Woods Health Center (1841 Clifton Rd, Atlanta GA 30029).

Course A meets MONDAYS

<table>
<thead>
<tr>
<th>Date</th>
<th>Speaker(s)</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Rebecca Dillard/Dr. Madeleine Hackney</td>
<td>Introduction: Research Regulations and Creativity in Later Life</td>
</tr>
<tr>
<td>2</td>
<td>Dr. Brent Hayek</td>
<td>Eyelid ptosis and the impairment of vision</td>
</tr>
<tr>
<td>3</td>
<td>Dr. Molly Perkins</td>
<td>End of life, palliative care, assisted living</td>
</tr>
<tr>
<td>4</td>
<td>Dr. Keith McGregor</td>
<td>Hand motor function</td>
</tr>
<tr>
<td>5</td>
<td>Dr. Arshed Quyyumi</td>
<td>Cardiovascular Health</td>
</tr>
<tr>
<td>6</td>
<td>Dr. Kenneth Hepburn</td>
<td>Dementia family caregiver research</td>
</tr>
<tr>
<td>7</td>
<td>Dr. Dan Kalman</td>
<td>Role of commensal microbiota in health span</td>
</tr>
<tr>
<td>8</td>
<td>Dr. Ted Johnson</td>
<td>Urinary incontinence</td>
</tr>
</tbody>
</table>

*If you are assigned to Course A but need to miss a class, feel free to attend a makeup in Course B on a Thursday!

Course B meets THURSDAYS

<table>
<thead>
<tr>
<th>Date</th>
<th>Speaker(s)</th>
<th>Topic</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Rebecca Dillard/Dr. Madeleine Hackney</td>
<td>Introduction: Research Regulations and Creativity in Later Life</td>
</tr>
<tr>
<td>2</td>
<td>Dr. Camille Vaughan</td>
<td>Bladder Matters in Aging Research</td>
</tr>
<tr>
<td>3</td>
<td>Dr. Kenneth Hepburn</td>
<td>Dementia family caregiver research</td>
</tr>
<tr>
<td>4</td>
<td>Dr. Bussey-Jones</td>
<td>(Primary Care Physician)</td>
</tr>
<tr>
<td>5</td>
<td>Dr. Thomas R. Ziegler</td>
<td>Research in specialized Nutrition Support</td>
</tr>
<tr>
<td></td>
<td>11/26 HAPPY THANKSGIVING!</td>
<td>(NO CLASS)</td>
</tr>
<tr>
<td>6</td>
<td>Dr. Dan Kalman</td>
<td>Role of commensal microbiota in health span</td>
</tr>
<tr>
<td>7</td>
<td>Dr. Emily Graubart</td>
<td>Common causes of vision loss in patients 65 and older</td>
</tr>
<tr>
<td>8</td>
<td>Dr. Molly Perkins</td>
<td>End of life, palliative care, assisted living</td>
</tr>
</tbody>
</table>

*If you are assigned to Course B but need to miss a class, feel free to attend a makeup in Course A on a Monday!
6.2 Sample Discussion Questions for DREAMS Part I Seminars

- What did you learn today?
- Did anything stand out or strike you as particularly interesting, novel, new?
- What did you know about the topic before you came here today?
- How will you use this information to improve your life or change your life?
- What would you tell your peer group about today’s lecture?
- What do you see as the most important thing to share with your peers?

6.3 Sample Discussion Questions for DREAMS Part II Seminars

For DREAMS Part II, it is recommended to use discussion questions tailored to the topic of each presentation, for example, the following questions can be used for the first lecture in the DREAMS Team series:

- What issues in aging related research are important to me?
- What areas of research or healthcare would I like to see changed (or conversely, stay the same)?
- What groups, networks, friends, peers could I educate about research and possibly help engage with clinical researchers at Emory or elsewhere?
- What are my preferred ways to be involved as an advocate and educator?

It is also possible, however, to use general questions which could be applied to any of the lectures, such as the following:

- Was there any information from today’s talk that surprised you, or stuck out to you as particularly interesting or important?
- What did you know about this topic before you came here today?
- How might you use the information from today’s talk as an advocate and educator?
- Who from my network could I share this information with?
6.4 Excerpt from Sample DREAMS Handout

WHY SHOULD YOU CARE ABOUT INFECTION?

- Infection accounts for 1/3 of all deaths in people over the age of 65.

INFECTION IS MORE COMPLICATED IN ELDERLY POPULATIONS

- Harder to detect
- Older individuals are more susceptible
- Higher frequency of antibiotic resistance
- Can affect mental status
- Can result in a decline in function
- Pneumonia, flu, UTI and C. dif are the most common
EMOTIONAL FITNESS

▶ Depression is not a normal part of growing older
▶ Often misdiagnosed and undertreated
▶ Enhances risk of infection
▶ Older adults at higher risk
▶ As high as 13.5% in some populations

This is treatable

EAT WELL

▶ Total energy requirement decreases
  ▶ Men: 2,000 - 2,800 cal/day
  ▶ Women: 1,600 - 2,200 cal/day
▶ Vitamin and mineral intake stays the same

How can you eat better?

Can vitamins help with infections?
6.5 Sample Knowledge Questionnaire (do not include title)

How familiar are you with informed consent processes?
VERY          SOMewhat          NEUTRAL          BARELY          NOT AT ALL

How much do you know about research subject protection measures, such as Institutional Review Boards (IRB)?
A LOT          QUITE A BIT       NEUTRAL          A LITTLE BIT    NONE

Before being a participant in the DREAMS program, were you ever asked to participate in research?
YES/NO

Before being a participant in the DREAMS program, had you ever participated in research?
YES/NO
If so, how many times? _______ What kind of study? ________________

What is your general attitude toward research that involves human participants?
NEGATIVE      GENERALLY NEGATIVE,      POSITIVE BUT WITH      POSITIVE      VERY
              BUT REALIZE Necessity         RESERVATIONS         POSITIVE

What is your general attitude towards participating in research yourself?
NEGATIVE      HESITANT          POSITIVE

What is your general attitude towards someone in your family or a close friend participating in human research?
NEGATIVE      HESITANT          POSITIVE

What do you think of participants being randomly assigned to different treatments in research?
NEGATIVE      HESITANT          POSITIVE

What do you think of participants being assigned to treatment vs. non-treatment in research?
NEGATIVE      HESITANT          POSITIVE

Do you think it’s necessary to examine “new” drugs using science and experiments before they are implemented in the doctor’s office and in hospitals?
NEVER          NOT ALWAYS, BUT SOMETIMES       MOST OF THE TIME       ALWAYS
How important do you think each of the following is to scientists when they conduct research? (for each question, circle one choice)

The wish to find new treatments/examinations?

Not important  Minor importance  Important  Very important

The wish to help patients?

Not important  Minor importance  Important  Very important

The wish to minimize total expenses in treatment and examination?

Not important  Minor importance  Important  Very important

The wish to promote their own career?

Not important  Minor importance  Important  Very important

The wish to increase knowledge generally?

Not important  Minor importance  Important  Very important

THANK YOU!!
6.6 DREAMS Presentations Evaluation

Please fill out this questionnaire regarding the seminars you attended in the DREAMS program. We are very interested in your feedback. Thank you for completing this evaluation!

Please indicate the extent to which you agree or disagree with the following statements:

The classes or activities have enhanced my knowledge/skills about the topics

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<thead>
<tr>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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The classes or activities will influence how I take care of myself

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<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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The classes or activities have provided me with information I can use

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<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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</table>

The quality of the classes or activities and its content was high

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<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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</table>

I would attend future programs, classes and activities offered by this group

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<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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</table>

I enjoyed participating in this program

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<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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If I could, I would continue participating in this program

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<th>STRONGLY AGREE</th>
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<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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</table>

I have been more physically active

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<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
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</table>

I have been more mentally active

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<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
</tr>
</thead>
</table>

Would you like to be considered for the DREAMS Team?  

<table>
<thead>
<tr>
<th>YES/NO</th>
</tr>
</thead>
</table>
What was your favorite presentation and why?

What was your least favorite presentation and why?

Additional topics I would like to see presented include:

Additional comments and/or suggestions for the programming team:

THANK YOU!!
7. Frequently Asked Questions

The following questions have come up in our implementation of DREAMS in interactions with community partners. It is possible that the answers we provide will help guide the implementation of your own project.

(1) The 8-week speaker series will be presented by local investigators and staff in year 1. Are these staff members all from XXX School of Medicine, or other research universities/institutions?

These staff members will be from the XXX School of Medicine predominantly, although we are open to including individuals from other universities and institutions.

(2) Is this only a series of presentations, or include medical guidance from Emory School of Medicine?

This program is only a series of presentations and no individual/direct medical guidance will be provided. The intention is not that the participants discuss their personal health, and no medical advice will be given. However, increasing general knowledge about the topic is a goal. Learning from the perspective of "health and wellness" is to provide a tangible benefit to the seniors to learn about the information.

(3) Patient advocate trainees will be identified from class participation? What is the process of selecting participants for Part II?

Part I will be moderated by a post-doctoral student interested in gerontological education and several undergraduate volunteers. Drs. Hackney and Perkins will attend some sessions. We will administer a survey at the beginning and end of the program asking participants if they have desire to attend Part II to become trained as a patient research advocate and undergo the curriculum. We will also ask participants to record notes and observations in notebooks that we provide them, and ask them for permission to review them later. Participants for Part II will be identified from the interactions and discussions taking place in Part I, the notes taken during the sessions, feedback from the post-doctoral and faculty presenters, and whether the individual has interest. We will also approach the activities’ directors/social workers, or other appropriate staff from the senior’s residence to determine the appropriateness of the particular individual for the training program.

*It may be preferred to present the note taking component as optional and exclude this from consideration for Part II, particularly if the group includes individuals with mixed literacy levels.

(4) Which and how many AHA-Owned communities will participate in this health training and research process?

As many as are interested. We have invited other non AHA-Owned communities to participate as well to have diverse representation.