

## **DGIM Project Summary**

**Name of Project:** Improving Primary Care Assessment and Diagnosis of Dementia: The Early and Accurate Detection and Diagnosis Toolkit

### **Investigator(s):**

Alissa Bernstein, PhD, MPH (PI)- [Alissa.bernstein@ucsf.edu](mailto:Alissa.bernstein@ucsf.edu)

Howard Rosen, MD (Co-PI)- [Howie.rosen@ucsf.edu](mailto:Howie.rosen@ucsf.edu)

Cindy Barton, RN, NP (Co-PI)- [cindy.barton@ucsf.edu](mailto:cindy.barton@ucsf.edu)

Loren Alving, MD (Co-PI)- [lalving@fresno.ucsf.edu](mailto:lalving@fresno.ucsf.edu)

### **Research question(s):**

- What are the facilitators and barriers to assessing, diagnosing, and managing dementia in the primary care setting?
- What do primary care providers think about the tools the CADC group created through Senate Bill 833 and how would they suggest improving these tools to facilitate their use?

### **Brief Background/Significance:**

The Alzheimer's Association reports that there are over 650,000 Californians suffering from Alzheimer's disease in 2018. Research suggests that almost half of people are not told of their diagnosis. Specialty physicians are most often relied on to provide work-up and diagnosis; however, the numbers of these specialists are not sufficient to meet the overwhelming need. In 2016, the 10 California Alzheimer's Disease Centers (CADCs) were charged by Senate Bill 833 with providing guidance to improve recognition and diagnosis by primary care providers. To fulfill this mandate, the CADCs created an expert panel to develop a toolkit that would support diagnosis based on standard of care and practice guidelines. However, the successful implementation of these tools will require input and feedback from primary care practitioners. The CADCs are seeking this feedback by organizing focus groups that would guide further revision of the toolkit for maximum utilization. This toolkit is designed to provide primary care providers with the tools necessary to recognize normal cognition, diagnose Alzheimer's disease and identify other cognitive problems requiring specialty referral. The materials provided focus on the questions recommended to take an appropriate history as well as guidance on how to interpret the answers. It identifies those answers that are consistent with normal aging (not worrisome), consistent with Alzheimer's disease, and those answers which indicate referral to a specialist is appropriate. The toolkit provides information about cognition and dementia diagnosis, including interpretation of brief cognitive testing, functional assessment, imaging and lab work, family history and the neurological examination. It also offers guidance in the form of scripts to guide difficult conversations around disclosure of diagnosis and reporting requirements for driving. Finally, information about billing codes and how to be able to successfully obtain reimbursement for these services in fee for service settings is included.

### **Inclusion/exclusion criteria (list)**

**Inclusion:** The population that will be studied are primary care providers, fellows, and residents. These include MDs, nurse practitioners, physicians' assistants, primary care fellows, and primary care or family medicine residents.

**Exclusion:** Those who are not primary care providers or primary care team members.

### **Method of contact/recruitment (be specific)**

(1) Dr. Howard Rosen and Cindy Barton, co-investigators, will contact primary care practice leaders, family practice leaders, and care practice leaders through a Dear Colleague letter (see *other documents- dear colleague info*). Practice leaders will be asked to recruit participants (MDs, NPs, PAs, residents, fellows) from their practices for the focus groups (see *other documents- dear colleague recruitment*).

(2) Once practice leaders have identified interested participants they will send the research team a list of providers along with contact information (email or phone number) who are interested in participating.

(3) The research team will reach out to interested participants to set up focus groups, divided by level of expertise (providers; fellows, residents).

(4) Two weeks prior to the focus group we will send a packet of information that includes a letter, an executive summary of the project, a dementia assessment toolkit, and an informational document.

(5) We will conduct focus groups at a conference room at the site of the primary care practice leader's choosing or on site at the Memory and Aging Center. Providers will be provided a \$50 gift card plus coffee and light snacks for their participation.

**Benefits/burden for participants (clearly identify potential for harm)**

**Benefits:** There will be no direct benefit to me from participating in this study. However, it is hoped that information gained from the project will help health professionals and health educators better understand how to care for and educate primary care providers around dementia assessment and management.

**Burdens:** 1. It is possible that answering questions about your clinical practice will be stressful. We will be able to stop or take a break at any time if I feel too uncomfortable.  
2. Confidentiality: Participation in research may involve a loss of privacy; but information will be handled as confidentially as possible. All records will be stored in a secure database and information transmitted by electronic mail will be protected by password or encryption. The UCSF Committee on Human Research and other University of California personnel also may review or receive information about me to check on the study. Participants' names will not be used in any published reports about this study. If information collected for this research is required by federal or state laws to be reported to appropriate officials, such as elder abuse, the researchers will follow such legal guidelines.

**Any benefits or burden to DGIM practitioners?** Same as above (DGIM practitioners are the participants in this study)

**Timeline for recruitment (projected start and stop dates):** August 2018-August 2019 (until 2 focus groups have been completed)

**Funding source:** CADC State Budget Project 833

**Potential for DGIM collaborators? (We encourage DGIM resident and fellow involvement in particular)** We hope that DGIM will collaborate through their participation in the focus groups, with the goal of improving the tools based on their feedback.

**Do you agree to notify us when recruitment is completed?** Yes

**Date form completed:** 8/9/2018