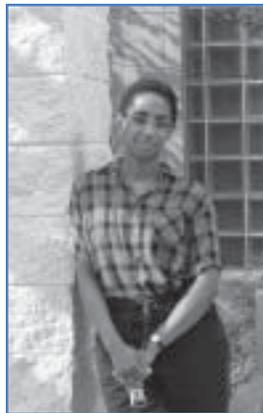


Senior Scientists:

- Carol M. Ashton, MD, MPH
- Rebecca J. Beyth, MD, MS
- Ursula K. Braun, MD
- Tracie C. Collins, MD, MPH
- Anita Deswal, MD
- Nancy Jo Dunn, PhD
- Hashem B. El-Serag, MD, MPH
- Marvella E. Ford, PhD
- Thomas Giordano, MD
- Laura Goetzl, MD, MPH
- Howard S. Gordon, MD
- Paul M. Haidet, MD, MPH
- Michael L. Johnson, PhD
- P. Adam Kelly, PhD, MBA
- Mark E. Kunik, MD, MPH
- Kimberly J. O'Malley, PhD
- Terri J. Menke, PhD
- Robert O. Morgan, PhD
- Herminia Palacio, MD, MPH
- Laura A. Petersen, MD, MPH
- Nancy J. Petersen, PhD
- Ken Pietz, PhD
- A. Lynn Snow, PhD
- Julianne Soucek, PhD
- Maria Suarez-Almazor, MD, PhD
- Nelda P. Wray, MD, MPH
- Mary J. York, PhD

## Community-Based Participatory Research

Tracy Urech, BA and Herminia Palacio, MD, MPH



**Herminia Palacio, MD, MPH**

The Community Liaison Team, one of six teams established as part of the HCQCUS Research Initiative, is exploring new territory for the Center and an area of emerging importance to health services research. Unlike the traditional database research method, community-based

participatory research seeks to actively involve the community throughout the research process, including having community members influence the research agenda. The goals of the team are to educate the Center's faculty about this method and how it is amenable to research questions and designs, and to engage the Center in discussion about the potential role community-based participatory research might play in the Center's future research endeavors.

This article serves to provide a review of literature published on community-based participatory research (CBPR) to elucidate to the reader: what is CBPR; what role it serves in the research arena; who is employing the paradigm and what topics are being researched; what are the benefits and drawbacks of using this approach; and what funding sources available to the research-scientist contemplating participatory research.

To understand community-based participatory

research, it may be helpful to understand what it is not. Israel et al (1998) explain that the philosophy of positivism has dominated approaches to scientific research. It stipulates a rigid, very controlled method of observing phenomena. They write, "This paradigm has influenced the development of research processes that elevate the presumed objectivity of scientific knowledge over subjective or experiential knowledge" (p. 176). CBPR's underlying theories, the "critical theory et al" and constructivism, emphasize the incorporation of the multiple factors and contexts (social, historical, economic and cultural forces) in the research evaluation and stresses an active, mutually beneficial relationship between the researcher and the participant. Community-based participatory research is not a research methodology (Israel et al 1998). It is a paradigm, a philosophy to problem solving, which unites the key players – the researcher and the community members – to produce the most appropriate outcomes. These include establishing interventions in the community, eliciting purposeful action, and inducing social change (Green and Mercer, 2001 and Israel et al, 1998).

To employ a community-based participatory paradigm to research endeavors, eight guiding principles have to be incorporated into the work. These include:

- (1) Recognizing the community as a unit of identity;
- (2) Building on the strengths and resources within the community;
- (3) Facilitating collaborative partnerships in all phases of the research;
- (4) Integrating knowledge and action for mutual

*(Continued on page 3)*

### Mission Statement

The Center impacts health and health care by conducting and translating outstanding research and by developing influential leaders in health outcomes, quality, access, utilization and costs.

*Reader's Digest* Interview Translates PAD Research into Practice

Tracie C. Collins, MD, MPH

An important HCQCUS core value is that our research should *impact the practice of health care*. One of the Center's junior scientists, Dr. Tracie Collins, exemplified this core value when she agreed to share her research on peripheral arterial disease (PAD) with Jon Conlon, a journalist from *Reader's Digest*. Dr. Collins feels that her research on PAD must reach beyond the scientific community. "To impact the practice of health care, it should reach consumers of health care... the patients." As her colleague, Dr. Laura Petersen, pointed out, "the readers of *Reader's Digest* are representative of the consumers of health care, and that is why her interview is so important." The following is an excerpt from her recent interview.

*Is it true that patients with peripheral arterial disease are at increased risk for heart conditions? Why? What is PAD?*

Yes. Patients with peripheral arterial disease or PAD are at increased risk for heart attacks and strokes. The disease is a marker of atherosclerosis in vessels of the heart and brain. At least 10% of patients with PAD have cerebrovascular disease and 28% have coronary artery disease. In one study of patients greater than 55 years of age who had leg symptoms of PAD, 20% had a nonfatal heart attack or stroke within 5 years from the time of the diagnosis of the leg symptoms. The older the patient with PAD, the more likely he/she will be at increased risk for a fatal or nonfatal heart attack or stroke. In PAD, the arteries that carry blood to the legs become narrowed or clogged. The disease can also involve the arteries of the arms but this is much less common. Because arm involvement is rare, PAD is commonly defined as atherosclerosis ("hardening of the arteries") of the abdominal aorta and arteries of the lower extremities. PAD is a marker or indication of atherosclerosis throughout the body, which includes both the coronary and cerebral vessels. The term PAD may sometimes be used interchangeably with peripheral vascular disease or PVD. The latter term is less accurate for patients with arterial narrowing limited to the arteries as PVD implies inadequate flow in any blood vessel, including veins.

PAD affects more than 10% of patients age 65 and more than 20% of patients aged 80 years and older. The diagnosis of PAD can be made by a simple bedside test in the office. The clinician places a blood pressure cuff on each arm and each ankle. The ratio of the systolic ("top blood pressure number") blood pressure in the ankle to that in the arm can diagnose this disease. This ratio can be referred to as the ABI (i.e., ankle-brachial index). A ratio of less than 0.9 is typically used to define disease. The risk factors for heart attack and stroke (e.g., diabetes, smoking, hypercholesterolemia, and hypertension) are the same as the risk factors for PAD.

Patients with PAD can have absolutely no symptoms of leg discomfort. However, the absence of symptoms is not protective against a heart attack or stroke. Patients with asymptomatic PAD also have an increased risk of heart attack and stroke. Patients with PAD, mild to moderate in severity, can have atypical leg cramps or the typical symptoms of cramping in the back of the legs that comes on while walking and resolves within ten minutes of the patient slowing down his/her pace or stopping. This pain is referred to as intermittent claudication or leg angina. As a result of leg pain, patients with intermittent claudication are often limited in their daily activities.

*What is the importance of treating PAD? What kinds of treatment are available? What is pain at rest?*

It is important to treat PAD to reduce the risk of the devastating outcome of limb loss, to limit leg pain and weakness, to reduce the risk of a heart attack or stroke, and to improve the quality of life.

Patients with PAD may have severe arterial narrowing with an ABI of less than 0.5. Patients with this degree of disease will often have leg pain not only with walking but also at rest (e.g., while lying down). For patients with severe PAD, lying in bed at night may be associated with severe leg pain such that dangling the leg over the side of the bed at night will be attempted by the patient to provide some relief. Additional symptoms of advanced PAD include ulcers around the ankles or on the feet,



Tracie C. Collins, MD, MPH

changes in the color of the skin of the lower legs, and possibly gangrene (i.e., dead tissue) overlying the lower extremities.

The treatment of PAD includes controlling risk factors (i.e., smoking cessation, blood sugar control in diabetes mellitus, blood pressure control, and cholesterol control). Patients without critical or severe PAD benefit from walking exercise which should be prescribed by a doctor. Exercise training, particularly supervised training in a vascular lab, can improve pain free walking distance, total walking distance, and the patient's atherosclerotic risk factors. In addition, vitamin supplementation with folic acid may also benefit patients with PAD. This is related to the affect of folic acid on normalizing the blood level of the amino acid homocysteine. Homocysteine levels are increased in patients with atherosclerosis and an elevated homocysteine level is a predictor of ischemic events (i.e., heart attacks and strokes).

Unless they have a contraindication, all patients with PAD should be on antiplatelet drug such as aspirin, clopidogrel, or ticlopidine. Patients with intermittent claudication can successfully be treated with a drug recently FDA approved in 1999, cilostazol. Like exercise therapy, cilostazol improves pain free and total walking distance in PAD patients with intermittent claudication. It also can be used along with exercise therapy.

For patients with severe intermittent claudication that is unresponsive to exercise and cilostazol, rest pain, leg/ankle ulcers, or gangrene, surgery is an option. Patients can be treated with lower extremity bypass surgery to relieve symptoms. Unfortunately, for patients with rest pain, leg ulcers, or gangrene that cannot be treated with bypass surgery, amputation or loss of limb is the final treatment.

Dr. Collins is a graduate of the University of Oklahoma College of Medicine and Harvard School of Public Health. Her research interests include the quality of care for patients with peripheral arterial disease, racial variation in the process of care, and doctor-patient communication. She is the recipient of the Robert Wood Johnson Foundation Minority Medical Faculty Development Award, a first in the VAMC's history.

### Community-Based Participatory Research (Continued from Page 1)

- benefit of all partners;
- (5) Promoting a co-learning and empowering process that attends to social inequalities;
- (6) Being involved in a cyclical and iterative process;
- (7) Addressing health from both positive and ecological perspectives; and
- (8) Disseminating findings and knowledge gained to all partners (Israel et al 1998).

Determination of the target community provides the foundation for action research. Israel et al (1998) note the importance of identifying the collective and individual identity of community. They define community as individuals who share a sense of identification, an emotional connection, a common symbol system, shared values and norms, and shared needs. It is vital to clearly define the community. MacQueen et al (2001) write, "In particular, the lack of an accepted definition of community can result in different collaborators forming contradictory or incompatible assumptions about community and can undermine our ability [the researchers] to evaluate the contributions of community collaborations to achievement of public health objectives" (p.1929). A Seattle Partners for Healthy Communities board member's comment regarding defining community succinctly describes the quagmire the researcher and community partners experience when toiling over this part of the research process. He noted, "[W]e demonstrated that there's no monolithic community. I think we've kind of debunked that myth, and I think that's very important. I've learned to ask now, when someone says, 'I'm from the community,' one of the first questions that comes up for me is: 'Which one?' ...

(Continued on Page 4)

# Cover Story

## Community-Based Participatory Research (Continued from Page 3)

not just ‘Which one are you from?’ but ‘Which one are you representing *at this point?*’” (quoted in Eisinger and Senturia, 2001, p. 522).

CBPR provides the researcher a new perspective. He or she is exposed to norms and attitudes of the community, what Israel et al (1998) note as “local theories”. The paradigm dictates not only the researcher to reap the knowledge from the community, but in turn, the academician is also to share his or her tools with the public. The academic moves out of the “ivory tower” and experiences first hand the perspectives of members of a marginalized community (Israel et al).

It is essential to incorporate all of the eight elements listed above to execute a meaningful CBPR research project. Israel et al (1998) note that these elements fall on a continuum, and the degree of participation will be based on the methodology and analytic plan of the research design. Such items will dictate how much community members will be able to contribute. It is vital to have all parties provide input at the beginning stage of the research when the decision on what topic to research is being formulated and at the concluding activities of translation and dissemination of results.

Community-based participatory research provides a broad based approach to the investigation of public health problems. The research field touts the randomized clinical trial as its gold standard, but this research approach concentrates on the study of the individual and does not account for the social and environmental forces affecting the subject’s performance in the trial. To examine the health disparities that exist between racial and ethnic groups, the research community has to begin employing mechanisms, such as CBPR, to account for the social determinants of health (Israel et al 1998). Lantz et al (2001) also note that ecological mindsets need to be used when determining such public health issues as “What issues in the community need to be studied?” and “What are the most appropriate measures to correct behaviors?” The ecological approach attempts to tease out the group effects of socioeconomic, cultural, and historical forces that are

obfuscated in the randomized clinical trial approach.

The Centers for Disease Control has funded three Urban Research Centers (URCs). They are the Detroit Community–Academic Urban Research Center, Seattle Partners for Healthy Communities, and the Center for Urban Epidemiological Studies in Harlem, New York. A four-year funding period starting in 1995 has been extended to the year 2003. The Urban Research Centers’ target populations are low-income, urban populations of color. Low-income populations are more vulnerable to poor health outcomes and disparities in health status. Using the social determinants of health model to explain health disparities among racial and ethnic groups is a priority of the URCs. Elements incorporated in the URC’s approach to research include the implementation of CBPR, the foremost goal being the involvement of community partners equitably in all phases of the research; the development and maintenance of the infrastructure needed to bolster collaborative networks; and the innovative study of the most urgent urban health issues to stimulate behavioral and political change in the target population and surrounding areas (Higgins and Metzler 2001).

The Detroit URC has achieved monumental success, accruing over \$11 million dollars in funding for 12 CBPR projects in the center’s first four years, and early 2001 figures put their funding dollars at 23 million plus. The Detroit URC comprises the University of Michigan School of Public Health at Ann Arbor, six community-based organizations, the Detroit Health Department, the Henry Ford Health System, and the CDC. The Center defines the community it aims to benefit with interventions and community capacity building activities geographically, identifying the east and southwest regions of Detroit as the target populations. Detroit Urban Research Center’s organizational structure is a 15-member board, participants representing the academic institution, the CBOs, and the health system involved. This group does not function as a community advisory board (CAB). There are no lay community members on the board. The board oversees, directs, and participates in all projects. Each specific project undertaken by the Detroit URC is guided by a steering committee, a group comprised of both board members and lay community members (Lantz et al 2001).



## Cover Story

The Detroit Urban Research Center has learned the importance of patience and flexibility since its inception in 1995. The fundamental process phase, organizational development, lasted 18 months. During this time, a mission statement and goals were formulated, operating procedures established, guidelines for implementing CBPR agreed upon, subcommittees formed, and a method to determine what priority areas were to be foci of the research was reached. Striking a balance between what the community wants to study and what the scholars want to study is vital to executing a successful community-based participatory research project. Community members, for the most part, demand intervention-based research projects while academicians are concerned not only with interventions but also contributing to the knowledge base in the field through descriptive and etiologic studies. Following the action phase, the Center focuses on the dissemination of project results and attempts to use the data to influence policy (Lantz et al 2001).

Lantz and colleagues understand the difficulties associated with community-based participatory research and the establishment of collaborative networks. The most precious resource needed to successfully develop the trust and institute the processes to lay the foundation is time -- and being flexible with a timeline. Also, during the beginning months of development, personnel involved, representatives from community-based organizations and/or researchers, will be frustrated because of the concentration on process-oriented activities as opposed to action-oriented tasks.

Funding agencies have recognized the appropriateness and the merits of community-based participatory research. These organizations include the W.K. Kellogg Foundation, the Henry J. Kaiser Foundation, the Robert Wood Johnson Foundation, the Centers for Disease Control, the National Cancer Institute, and the World Health Organization (Israel et al 1998). Not only are funding agencies this research approach, but also academic institutions are designing classes to train public health students to have the tools to effectively execute community-based participatory research projects. Such schools include the University of California-Berkeley School of Public Health, the University of Washington School of Nursing, the University of Michigan School of Public Health, and the University of

North Carolina-School of Public Health.

John Milton once wrote in *Paradise Lost* about how no man is an island. Community-based participatory research embodies this idea and seeks to study the community as a whole with the community being an equitable participant in the research. No one philosophy to research will cure all the ills of society. Eisinger and Senturia (2001) writes, "... this paradoxical aspect of participatory research: Sometimes the very actions that are designed to sidestep or correct the pitfalls of more traditional research create new dilemmas and difficulties" (p.532).

#### References:

Green LW and Mercer SL. Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *AJPH*, 91:1926-1929, 2001.

Israel BA, Schulz AJ, Parker EA, and Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*, 19: 173-202, 1998.

MacQueen KM, McLellan E, Metzger DS, Kegeles S, Strauss RP, Scotti R, Blanchard L, and Trotter RT. What is community? An evidence-based definition for participatory public health. *AJPH*, 91: 1929-1937, 2001.

Higgins DL and Metzler M. Implementing community-based participatory research centers in diverse urban settings. *J Urban Health*, 78: 488-494, 2001.

Lantz PM, Viruell-Fuentes E, Israel BA, Softley D, and Guzman R. Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit. *J Urban Health*, 78: 495-507, 2001.

Eisinger A and Senturia K. Doing community-driven research: a description of Seattle Partners for Healthy Communities. *J Urban Health*, 78: 519-534, 2001.

Ms. Urech is a graduate of Huntingdon College, Montgomery, Alabama. She staffs and is a regular contributor to the HCQCUS Community Liaison Team.

Dr. Palacio is a graduate of Mount Sinai School of Medicine, New York, NY and the University of California Berkeley School of Public Health. From

*(Continued on Page 11)*

# Funding Updates

## New Research Grants

*Note: In the last issue of The Research Monitor, Dr. Mark Kunik's new grant information was incorrect. The editor apologizes for the miscommunication. The correct information is listed below.*

PI: **Mark E. Kunik, MD, MPH**

Source: VA Investigator Initiated Research Grant

Title: "A Cognitive-Behavioral Intervention for Depression and Anxiety in COPD"

Amount/Period: \$855,300; 1/02-12/06

Description: The literature and our preliminary studies find that in COPD patients, psychosocial factors such as anxiety and depression affect quality of life and functioning over and above what would be expected given the severity of their disease. Thus, in order to improve quality of life and functioning in the 20 percent of COPD patients with significant anxiety and/or depression symptoms, interventions are needed to help these individuals manage their psychosocial symptoms. Considering the wealth of research that has documented the utility of cognitive behavioral therapy (CBT) in treating anxiety and depression, CBT shows promise as a self-management intervention to improve quality of life in this population. If our hypothesis is correct (that COPD patients receiving CBT/usual care will show greater improvement when compared to COPD patients receiving COPD Education/usual care), a more proactive approach can be taken to ensure that COPD patients with anxiety and depression receive appropriate care/interventions, which ultimately may improve their quality of life and functioning, and potentially reduce long-term health care usage.

PI: **Maria Suarez-Almazor, MD, PhD**

Source: National Institute of Arthritis, Musculoskeletal and Skin Diseases

Title: RO1 AR47858-01; "Treatment Adherence in Minorities with Rheumatic Disease"

Amount/Period: \$2,379,630; 4/02-3/07

Description: The outcome of patients with rheumatic disease, in particular rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) is

variable and often unpredictable, and important differences have been observed across racial groups. Patients often show poor adherence to therapy, but the determinants and outcomes of compliance-related behaviors have not been adequately documented. We hypothesize that some of the ethnic differences in the outcome of these diseases may be related to degree of compliance with physician recommendations. The overall objective of this study is to quantify adherence to medical recommendations in patients with RA and SLE from diverse ethnic backgrounds, and to determine which are its predictors and outcomes, with an emphasis on psychosocial factors and medical interaction issues. The study will: a) compare attitudes and behaviors toward adherence to treatment in patients with RA and SLE from diverse ethnic backgrounds; b) assess the role of patient beliefs, expectations and attitudes about their disease on their adherence to treatment; c) assess the role of selected elements of the medical interaction on patients' compliance; d) evaluate ethnic differences in compliance in the context of a modified Health Belief Model (HBM); and e) determine the impact of non-compliance on patient outcomes. *Phase 1* will use focus groups (including White, Hispanic, and Black patients) to explore the views of patients with RA and SLE toward adherence to treatment, barriers and perceived benefits. The groups will also provide information to develop scales that measure barriers and expectations in the context of the HBM. *Phase 2* will be a 2-year cohort study of patients with RA and SLE from diverse ethnic backgrounds which will evaluate the determinants of adherence to treatment on the basis of the HBM, and will also examine health outcomes at the end of the 2 years according to the degree of adherence.

PI: **A. Lynn Snow, PhD**

Source: National Institute of Mental Health  
Title: RO3 MH64033-01; "Severely Demented Individuals: Assessing Their Pain"

Amount/Period: \$75,250; 4/02-3/03

Description: Despite reported pain prevalences as high as 75 – 80%, studies consistently report that pain is under-diagnosed and under-treated in the nursing home. Demented individuals, who



constitute the majority of nursing home residents, are particularly at risk for under-diagnosis and under-treatment of pain because of their decreased self-report capacity. Currently, no pain assessment instrument exists that is simultaneously brief, easy to administer, reliable, well-validated, and inclusive of a variety of pain behaviors typical of dementia patients.

The goal of this project is to comprehensively evaluate and refine the NOPPAIN (NON-communicative Patients Pain Assessment INSTRUMENT), a brief standardized nursing assistant-administered pain assessment instrument to be used with severely demented individuals. The NOPPAIN items were developed with the assistance of an expert clinical, research, and psychometric panel in a recent pilot study. The instrument emphasizes the assessment of pain through direct questions and observations of specific pain behaviors during the performance of common patient care tasks.

The Specific Aims of the proposed project are: (1) to demonstrate the clinical feasibility of the NOPPAIN, including ease of administration, time required for administration, and ability of untrained nursing assistants to administer the instrument; (2) to demonstrate the construct validity of the NOPPAIN in severely demented individuals; (3) to demonstrate the inter-rater, internal consistency, and test-retest reliability of the NOPPAIN in severely demented individuals. Participants will be moderately to severely demented individuals from 5-7 nursing homes. NOPPAIN validity evidence will be obtained by comparing NOPPAIN ratings of a low pain probability group (patients with no pain-related conditions) to a high pain probability group (patients with pain-related conditions) ( $n = 150$  for both groups). Validity evidence will also be obtained by comparing the change between NOPPAIN ratings taken one hour apart in a control group to the change between pre- and post-medication administration NOPPAIN ratings in a group receiving a *prn* analgesic medication ( $n = 35$  for both groups). Inter-rater reliability will be evaluated by both comparing four nursing assistant raters who will observe NOPPAIN administrations live, and by comparing four nursing assistant raters who will observe videotapes of the same NOPPAIN administrations.

PI: **Michael L. Johnson, PhD**

Source: Pfizer

Title: "Hypertension, Hyperlipidemia, Diabetes Study 1"

Amount/Period: \$149,184; 3/02-2/03

Description: Using the VISN 16 and VISN 20 data warehouses we will identify a cohort of hypertensive patients, diabetic patients and hyperlipidemic patients. These cohorts will be identified based on algorithms provided by Pfizer consisting of a combination of diagnostic, pharmacy and laboratory and vital signs information. For example, the Diabetes cohort will be created by identifying all patients with the following characteristics: at least one prescription of insulin or an oral hypoglycemic agent; or at least one abnormal hemoglobin A1c (defined as greater than 6.5%); or at least two outpatient diagnoses of diabetes; or at least one hospital discharge with a primary diabetes-related diagnosis. Specific diagnosis codes for each disease, and specific medications for each disease definition will be determined by the Baylor project team and Pfizer team. See Appendix for complete algorithms for each disease.

VISN 16 and VISN 20 are two of the 22 geographically distinct regional organizational networks within the VA. VISN 16 is the largest single network. In FY98 (October 1997 to September 1998) approximately 12% of the 3.4 million veterans treated in the VA were cared for in these two VISNs. Since the three conditions of interest are extremely common in VA patients we expect our cohorts to contain around 200,000 patients. All records for a two-year period beginning October 1, 1999 (FY00) and ending September 30, 2001 (FY01) will be searched to create the study cohorts.

PI: **Laura Petersen, MD, MPH**

Source: VISNs 5, 6, 12 (VA Contract)

Title: "Using DCGs to profile and forecast facility budgets in VISNs 5, 6, and 12"

Amount/Period: \$185,050; 2/02-1/03

Description: There is no standardized methodology at the national level for allocating resources from the VA Network to the VA facility level. Any methodology used must fairly compensate facilities that provide tertiary referral care. In previous work done at the

*(Continued on Page 9)*

# Funding Updates

## Recent Publications

**Hashem B. El-Serag, MD, MPH**; AC Mason; **Nancy J. Petersen, PhD**; CR Key. "Epidemiological differences between adenocarcinoma of the oesophagus and adenocarcinoma of the gastric cardia," *Gut*, 2002;50:368-72.

## Abstract:

**Background.** It has been suggested that gastric cardia adenocarcinoma (GCA) is a distinct entity from oesophagus adenocarcinoma (OA). We examined several epidemiological features of GCA and OA in the USA to elucidate differences/similarities between these malignancies.

**Methods.** Using the database of Surveillance, Epidemiology, and End Results (SEER) program, we examined incidence rates for temporal changes, and ethnic and age distribution, and performed birth cohort analyses for cases with morphological and histological confirmed OA or GCA.

**Results:** The age adjusted incidence rates of OA rose progressively, reaching 1.8 per 100 000 (95% confidence interval 1.7-1.9) during 1987-1991 and 2.5 per 100 000 (2.3-2.6) during 1992-1996. In 1992-1996, Whites were affected five times more than Blacks, and men eight times more than women. A significant increase in incidence occurred among younger persons aged 45-65 years. Irrespective of age, OA was characterized by higher incidence rates among more recent birth cohorts: a 40% increase in incidence for each five year increase in the date of birth—a "birth cohort effect". On the other hand, the incidence rates of GCA reached their highest level of 3.3 per 100 000 (3.2-3.4) in 1987-1991 and subsequently declined during 1992-1996 to 3.1 per 100 000 (3.0-3.3). Whites were affected twice more than blacks and men five times more than women. Most patients with GCA were older than 60 years with no increase among younger persons and no birth cohort effect ( $p=0.99$ ).

**Conclusion:** Several significant epidemiological differences exist between OA and GCA. These differences suggest that these two malignancies are separate entities with different risk factors.

**Tracie C. Collins, MD, MPH**; Jack A. Clark, PhD; **Laura A. Petersen, MD, MPH**; Nancy R. Kressin, PhD. "Racial differences in how patients perceive physician communication regarding cardiac testing." *Medical Care*, 2002;40(1):I-27-34.

## Abstract:

**Objectives.** Recent studies documenting racial variation in the use of cardiac procedures highlight the need to understand if there are racial differences in processes of communication and decision making. Investigations of patients' perceptions of their interaction with providers regarding cardiac testing were conducted.

**Methods.** Four focus groups were convened with 13 patients who had undergone cardiac stress testing with positive results, stratified by race (white vs. black). Verbatim transcripts of discussions of their interactions with providers relating to their cardiac problems were analyzed qualitatively by a team of behavioral scientists and general internists to identify significant dimensions of communication and patient-provider relationships.

**Results.** Four domains of communication were identified that appeared to bear on patients' comfort and preferences regarding cardiac procedures. First, the substance of the information that was provided by physicians and other providers was described as incomplete, vague, ambiguous, and unclear. Second, some recommendations either were inconsistent with expectations or awakened fears based on distressing previous experiences. Third, patients said they needed to be convinced of the need for additional, invasive tests and therapeutic procedures, and in some cases providers' arguments failed in this regard. Fourth, the patients highlighted the importance of trusting their provider. Although there were no apparent differences by race in patients' perception of the information they received, black patients consistently expressed a preference for building a relationship with physicians (*trust*) before agreeing to an invasive cardiac procedure, and just as consistently complained that trust was lacking. Conversely, white patients tended to emphasize that they were inadequately convinced of the need for recommended procedures.

**Conclusions.** This study provided qualitative

information regarding patients' perceptions of physician-patient communication and racial differences in such perceptions. For both black and white patients, we found problematic aspects of the patients' experiences regarding communication about cardiac testing. Our findings suggest that although patients desire clarity from physicians, they are often confused regarding the information received. Both a lack of substance and vagueness of the information received may be linked to feelings of mistrust toward physicians when considering further diagnostic testing. Mistrust may be a source of some of the documented racial variation in health care utilization.

**Tracie C. Collins, MD, MPH; Michael L. Johnson, PhD;** William Henderson, PhD; Shukri F. Khuri, MD; Jennifer Daley, MD. "Risk factors for lower extremity non-traumatic amputation in peripheral arterial disease: is race/ethnicity an independent factor?" *Medical Care*, 2002;40(1):1106-1116.

**Abstract:**

**Objectives.** To determine if race/ethnicity is independently associated with an increased risk for nontraumatic lower extremity amputation versus lower extremity bypass revascularization among patients with peripheral arterial disease (PAD).

**Methods.** Data were analyzed from the National VA Surgical Quality Improvement Program (NSQIP) and from the Veterans Affairs Patient Treatment File (PTF). Race/ethnicity was defined as non-Hispanic white, black, or Hispanic. Variables that were univariately associated ( $P$  is less than or equal to 0.05) with the outcome of amputation were placed into a multiple logistic regression model to determine independent predictors for the dependent variable, lower extremity amputation versus lower extremity bypass revascularization.

**Results.** Three thousand eighty-five lower extremity amputations and 8409 lower extremity bypass operations were identified. Among all cases included, there were 416 Hispanic patients (3.6%), 2337 black patients (20.3%), and 8741 non-Hispanic white patients (76.1%). Among all variables within the model, Hispanic and black race were each associated with a greater risk for amputation than a history of rest pain/gangrene (Hispanic

*(Continued on Page 11)*

**New Grants**

*(Continued from Page 7)*

request of the leadership of Networks 5, 6, and 12, we developed and assessed the impact of a patient health-based budget allocation method on VA facility budgets in the three Networks using Diagnostic Cost Groups (DCGs). For this contract, more in-depth analyses will aid in understanding the usage of DCGs at the VA facility level. The objectives of this contract include: exploring reliance issues; profiling costs across facilities; forecasting budgets for facilities; assessing variations in cost for special care groups; and evaluating long term care availability.

**PI: P. Adam Kelly, PhD, MBA**

Source: Department of Veterans Affairs

Title: MRR 02-114; "Just-In-Time IRB Review Evaluation"

Amount/Period: \$100,000; 4/02-3/03

**Description:** The major goal of this project is to evaluate the impact that just-in-time IRB review has on IRBs, principal investigators and their staff, and scientific review boards within the Department.

Just-in-Time (JIT) management practices have long been regarded as both a tool for organizational cost-effectiveness and a hallmark of Total Quality Management. Following the principles set forth by Deming and Juran in the 1970s and implemented by Japanese auto makers, whose perfection of the "kanban" system of JIT manufacturing drew worldwide attention, the many subsequent successful implementations of JIT have established it as an ideal to be achieved by excellent organizations.

VA HSR&D has recognized this and, in keeping with its mission to achieve excellence in all areas of health services delivery to veterans, has implemented JIT merit review on a pilot basis for the period of April 1, 2002 through March 31, 2003. We are evaluating the effectiveness of this JIT implementation, with the intent of highlighting the cost-effectiveness and accompanying enhancements to merit review quality that JIT engenders, while alerting HSR&D of actual or potential pitfalls that may arise as unintended consequences of JIT merit review.

# Staff News

On April 23, 2002, the **Houston Center for Quality of Care & Utilization Studies** celebrated its first anniversary in its new office in the former Nabisco building at the corner of Holcombe and Almeda. HCQCUS, a Veterans Affairs Research and Development Center of Excellence and Section of Health Services Research, Department of Medicine, Baylor College of Medicine, was the first to occupy space in the building that is now owned by Texas Medical Center.

**Carol M. Ashton, MD, MPH**, HCQCUS director and senior scientist, was recognized by The University of Texas MD Anderson Cancer Center's The Center for Research on Minority Health for her contributions to health disparities research during National Minority Cancer Awareness Week. Dr. Ashton was awarded a plaque at a luncheon in recognition of her leadership of the Houston EXCEED (Excellence Center to Eliminate Ethnic/Racial Disparities) Program, a program project grant funded by the Agency for Healthcare Research and Quality, that reflects this year's theme: "Bridging the Gap: Science Benefiting the Community."

**Hashem B. El-Serag, MD, MPH**, HCQCUS senior scientist, will present "Hepatocellular Carcinoma, Non-Invasive Monitoring of Hepatitis C Use and Interpretation of Virologic Tests HCC and Hepatitis C Screening for HCC: Systematic Review" at the NIH Consensus Development Conference, *Management of Hepatitis C: 2002*. Dr. El-Serag is a member of an esteemed panel of expert physicians who will present the information for public discussion at the Natcher Conference Center of the National Institutes of Health in Bethesda, Maryland on June 10-12. The National Institute of Diabetes and Digestive and Kidney Diseases will host this two-and-a-half day conference update on Hepatitis C with the aim of reviewing the most recent developments regarding management, treatment options, and the widening spectrum of potential candidates for treatment. Additionally, this spring, Dr. El-Serag was an invited speaker on hepatocellular carcinoma at the Yale University Symposium and the University of Michigan, Ann Arbor.

Dr. El-Serag has been invited to join the editorial board of the *American Journal of Gastroenterology* for a three-year term. The *Journal* has emerged as a leader in clinical gastroenterology with the aim of bringing the *Journal* to an even wider audience and

to incorporate the very best in clinical gastroenterology research and ideas. In addition, Dr. El-Serag was recently recognized by the *Annals of Internal Medicine* for his exceptionally fine quality work. The quality and timeliness of Dr. El-Serag's reviews placed his work for *Annals* in the top 30 percent of all reviews in 2001. In his praise for Dr. El-Serag, *Annals* editor, Dr. Harold C. Sox, stated that he is interested in seeing outstanding reviewers, like Dr. El-Serag, get the credit they deserve."

**Howard D. Gordon, MD**, was appointed a reviewer of the *American Journal of Medicine*, 2002.

**Michael L. Johnson, PhD**, was honored as a Top 5% Scientific Reviewer, *Medical Care*, 1997-2001. Dr. Johnson also presented the results of his Lansoprazole study at the Academy for Health Services Research and Health Policy in Washington, DC, and at the International Society for Pharmacoeconomics and Outcomes Research conference in Arlington, Virginia.

**P. Adam Kelly, PhD, MBA**, presented, "Further evaluation of automated essay score validity," at the annual meeting of the National Council on Measurement in Education in New Orleans in April.

**Herminia Palacio, MD, MPH**, was selected by the National Academy of Sciences Institute of Medicine to sit on the Public Financing and Delivery of HIV Care Committee through March 2003. This committee will explore and address the effectiveness and efficiency of service delivery within the context of a changing health care and therapeutic environment. This study is intended to develop a policy framework and recommendations that improve the continuity, equity and efficiency of the systems of HIV care, and fill identified financing and servicing gaps. This framework will consider the various funding streams that support care for persons living with HIV/AIDS and recommend ways to create a more equitable, cost-effective, high quality, comprehensible and easily negotiable system of care. Dr. Palacio has experience in policy development as well as health services and health policy research in the areas of HIV and substance use.

**Laura A. Petersen, MD**, is a member of the Selection Committees, *Best Paper of the Year Award*, and *Eisenberg Research Award* (Society's highest research



award for senior members) Society of General Internal Medicine, 2002; and Member, Grant Review Panel, Sandra A. Daugherty Foundation, 2002-Present. Also this spring, Dr. Petersen was invited to give presentations for the VERA Patient Classification Work Group in Denver and Las Vegas; Robert Wood Johnson Foundation National Advisory Committee; and was invited to brief newly-appointed VA Under Secretary for Health, Dr. Robert Roswell.

**Nancy Petersen, PhD**, was appointed an ad hoc reviewer for *Medical Care*, 2002.

**Matt D. Price, MS**, HCQCUS chief communications officer and **Paul M. Haidet, MD, MPH**, HCQCUS senior scientist, were co-authors of "Self Reported Assessments of Quality of Life After Total Knee Arthroplasty" published in the Winter 2002 issue of *The Occupational Therapy Journal of Research*.

**Siddharta Reddy, MPH**, HCQCUS project staff, was co-author of "Age at acquisition of *Helicobacter pylori* infection: a follow-up study from infancy to adulthood" published in the March 16 issue of *The Lancet*.

(Continued on Page 12)

#### Recent Publications

(Continued from Page 9)

race 1.4, 95% CI 1.1, 1.9; black race 1.5, 95% CI 1.4, 1.7; rest pain/gangrene 1.1, 95% CI 1.0, 1.3). The final model had a *c* statistic of 0.83.

**Conclusions.** Hispanic race and black race were independent risk factors for lower extremity amputation in patients with PAD. Although the burden of certain atherosclerotic risk factors (e.g., diabetes and hypertension) is higher in minority patients, the impact of this burden does not account for the increased risk for the outcome of lower extremity amputation in these two populations. Further research is needed to better understand the reason(s) why race/ethnicity is independently associated with poor outcomes in PAD.

**Laura A. Petersen, MD, MPH**, "Racial differences in trust: reaping what we have sown?" *Medical Care*, 2002;40:79-82. Editorial.

## New Staff

Tracy Barrera Administrative Staff

Kimberlee Benn, MHA Post-Master's Fellow

Heather Dyson Project Staff

Sunshine Gage Project Staff

Maria Garcia Popa-Lisseanu, MD Post-Doctoral Fellow

Karen Garibaldi, MD Post-Doctoral Fellow

Lawrence Giuffre Administrative Staff

Rose Peralta Administrative Staff

K. Marie Rogers Administrative Staff

Diane Simmons Administrative Staff

Emily Teasdale Project Staff

## Appointments

Jessica Davila, PhD Post-Doctoral Fellow to Senior Scientist at the conclusion of her fellowship in October.

## Welcome and Congratulations!

#### Community-Based Participatory Research

(Continued from Page 5)

1998 through 2001, she served as Special Policy Advisor to the Director, San Francisco Department of Public Health. She was also on faculty in the AIDS/Oncology Division, Department of Medicine, University of California San Francisco School of Medicine from 1993-2001. While in San Francisco she was actively involved in numerous HIV-related studies including the Women's Interagency Cohort Study. Her responsibilities at the San Francisco Department of Public Health included taking a leadership role in developing and implementing innovative strategies to expand treatment for persons with opiate addiction. In Houston she is conducting a project focused on evaluating the local impact of new federal substance abuse treatment legislation.

# Staff News

## Executive Team:

Carol M. Ashton, MD, MPH  
Director, HCQCUS

Nelda P. Wray, MD, MPH  
Chief, Baylor HSR Section

Michael L. Johnson, PhD  
Associate Director, HCQCUS

## Management Team:

W. Keith Neeley, MBA  
Chief Operating Officer

Dianna Densmore, MS  
Chief of Project Staff

Shannon E. Dwyer, BA  
Chief of Business Development

Theresa L. Foss, BS  
Chief of Human Resources

Paul J. Gregor, PhD  
Chief Information Officer

Nancy J. Petersen, PhD  
Chief of Statistical Analysis and  
Data Processing

Matt D. Price, MS  
Chief Communications Officer

Angelita H. Vinluan, CPA  
Chief Financial Officer

## Post-Doctoral Fellows:

Julie Aniol, PhD  
Serena Chu, PhD  
Jessica Davila, PhD  
Maria Garcia Popa-Lisseanu, MD  
Karen Garibaldi, MD  
Damien Mallat, MD  
LeChauncy Woodard, MD

## In This Issue...

### Feature Article:

*Reader's Digest* Interview  
Translates PAD Research  
into Practice ..... Page 2

Cover Story, *continued* ..... Page 3

Funding Updates ..... Page 6

Publications ..... Page 8

Staff News ..... Page 10

## Staff News

(Continued from Page 11)

Several HCQCUS investigators recently made presentations at the 25th Annual Meeting of the **Society of General Internal Medicine (SGIM)**. SGIM is one of the world's preeminent organizations devoted to research, education, and practice in general internal medicine. Competition for presentations at the national SGIM meeting is typically intense, reflecting the high levels of scholarship achieved by presenters. This year, HCQCUS investigators made presentations in every venue available at SGIM; these venues included oral research abstracts, research posters, pre-course and workshop presentations, interest groups, clinical vignettes, and innovations in medical education exhibits. In addition, 5 HCQCUS investigators, presented in more than one venue, reaching a level of achievement that is unparalleled among health services research sections.

HCQCUS has been fortunate and honored to host several esteemed guest speakers and visiting professors this spring. They include: **Lee Sechrest, PhD**, Professor, Department of

Psychology, University of Arizona (Tucson); **Andrew Schafer, MD**, Chairman, Department of Medicine, Baylor College of Medicine; **Alvin Tarlov, PhD**, The Texas Institute for Society and Health; and **Lisa Rubenstein, MD, MSPH**, Director, VA HSR&D/RAND/UCLA/UCSD Center of Excellence for the Study of Healthcare Provider Behavior, Sepulveda, California. We sincerely thank each of them for sharing their expertise with us.

The new HCQCUS web site was unveiled on May 8. Its improved design and functionality will help to highlight the Center's history, current achievements, and future goals and greatly improve our ability to communicate our mission to our customers and communities. Our nationally recognized Center and team of scientists and staff have a lot to be proud of, and we are very excited to share that pride with you on our site. Matt D. Price, MS, chief communications officer and webmaster wishes to thank Kimberlee Benn, MHA, for her insightful suggestions and abundant talents while assisting with the creation of the web site. Please visit our web site at <http://www.hsrh.houston.med.va.gov>.



713.558.4500 Phone  
713.748.7359 Fax  
[www.hsrh.houston.med.va.gov](http://www.hsrh.houston.med.va.gov)

**Courier Address:**  
2450 Holcombe Boulevard, Suite 01Y  
Houston, Texas 77021

**Houston Center for Quality of Care & Utilization Studies**  
Veterans Affairs Medical Center (152)  
2002 Holcombe Boulevard  
Houston, Texas 77030