Message from the Director
Richard A. Deyo, MD, MPH

This issue of our Newsletter highlights research on child health that’s underway in the realm of Community and Practice Research. These projects are based at both OHSU and Kaiser CHR, and include work in the Department of Family Medicine as well as Pediatrics.

Some may not realize that OHSU is home to a center for improving access to national data on child health, measuring the quality of care for children, and better informing health policy initiatives. This program, the Child and Adolescent Health Measurement Initiative, or CAHMI, is based in the OHSU Department of Pediatrics and is headed by Dr. Christina Bethell. The data housed by the program are widely used by state government agencies as well as academic investigators and others. Similarly, Dr. Jen DeVoe in Family Medicine has been using statewide Medicaid data and national data from the Medical Expenditure Panel Survey (MEPS) to study the impact of policy changes on children’s insurance coverage.

The importance of studying such population-based data was highlighted in a recent commentary (Booth CM, Mackillop WJ, “Translating New Medical Therapies into Societal Benefit: The Role of Population-Based Outcome Studies”. JAMA 2008; 300: 2177-9). The authors noted that benefits suggested in randomized clinical trials are sometimes not borne out on a population level, citing studies of spironolactone for congestive heart failure. RCT’s found a 30% improvement in mortality, but population databases failed to show a decrease in hospitalization or death, and uncovered a rise in hospitalization for hyperkalemia. Conversely, population-based studies confirmed the benefit of adding chemotherapy to radiation therapy in the treatment of invasive cervical cancer. The survival benefit closely matched the results expected from clinical trials.

Such studies highlight the value of population-based data resources in improving community health and guiding health policy decisions. We anticipate a growing role for the OCTRI CPR program in supporting local access to such data.

- Rick

THE CHILD AND ADOLESCENT HEALTH MEASUREMENT INITIATIVE

The CAHMI, housed within the OHSU Department of Pediatrics and directed by Christina Bethell, PhD, MBA, MPH, is a national initiative dedicated to:

- the development of scientifically valid, family-centered approaches to measuring & improving the quality of health care for children & adolescents
- the advancement of data-driven and evidence-based policy and advocacy

Two major initiatives of the CAHMI are:

1. Provide easy access to population-based data on child and youth health through the National Data Resource Center for Child and Adolescent Health (DRC)
2. Develop, test and support patient-centered methods for assessing the quality of health care provided to children and youth through the Program for Consumer-Centered Quality Measurement & Improvement

Look inside for more about CAHMI...
www.cahmi.org
And other population-based pediatric research
SHINE: Healthy Lifestyle Practices for Overweight Teen Girls
A behavioral health weight control program conducted through the Kaiser Permanente Center for Health Research

For teened girls, body image can be an enormously loaded issue. Peer pressure, hormonal changes, and the influence of a popular culture that celebrates thinness and early sexuality—these are among the factors that can skew a growing girl’s perception of what “normal” can be. As girls confront issues of healthy eating and body image, psychological health is tested; so too is physical health, as teens may put healthy brain, bone, and organ development at risk with poor nutrition. Overweight teens suffer disproportionately; their health may already be compromised, poor habits reinforced, and social stigmas further eroding self-image.

As a psychologist and senior investigator at the Kaiser Permanente Center for Health Research (CHR), Lynn L. DeBar, PhD, knew well the challenges faced by today’s teen girls, and she posited that early intervention could be an antidote. Dr. DeBar wanted to see whether primary-care-based intervention could help overweight teen girls adopt healthy lifestyle practices. So she and fellow CHR senior investigator Dr. Vic Stevens created SHINE—the Study for Healthy and Integrated Nutrition and Exercise, a four-year study to examine how dietary changes, activity changes, and family and peer support impacts weight and associated morbidity (e.g., disordered eating, depression). They received funding from The National Institute of Child Health and Human Development, and SHINE was launched in the summer of 2005.

From select Kaiser Permanente Northwest primary care medical offices, the investigators recruited 215 teen girls aged 12 to 17 with a body mass index above the 90th percentile. All teens and parents received information supporting a healthy lifestyle and had an initial visit with their primary care provider. Then participants were randomly assigned to one of two groups for a two-year period: (1) a behavioral weight control program specifically tailored for teen girls or (2) usual care.

For the intervention arm, the teens’ primary care providers received feedback about their patients from the study describing participants eating and physical activity habits and instructions on how to best work with these teens and their families. The behavioral weight control program included 16 group meetings for teens, 12 separate meetings for parents, telephone follow-up with study staff, and customized feedback from the teen’s primary care provider.

About one third of the participants have completed their two-year assessment. Drs. DeBar and Stevens are enthusiastic about how the study has progressed, and review of preliminary data suggests that the program has helped. The study closes next summer, and Dr. DeBar looks forward to the data analysis phase, hoping to have results by early fall 2009.
The National Data Resource Center for Child and Adolescent Health (DRC) makes available to the public federally funded population-based data on child and youth health, health services and utilization and health system performance data. It is supported through a three year competitive Cooperative Agreement with the Maternal and Child Health Bureau, Health Resources and Services Administration, US Dept of Health & Human Services.

Datasets:
Currently the DRC website includes national and state-based data on over 100 indicators from the 2003 National Survey of Children’s Health (NSCH) and the 2001 and 2005/2006 National survey of Children with Special Health Care Needs (NS-CSHCN). The 2007 NSCH will be available through the DRC in early Spring 2009. CAHMI researchers are also leading components of the design and validation of the new 2009-2010 NS-CSHCN, including testing with parents of children with special health care needs who receive services through OHSU.

The DRC website features:
- Point-and-click navigation to identify indicators or topics of interest
- Fully formatted, annotated, downloadable “print-and-go” tables and graphs of results
- Options to iteratively compare findings across any two states or all states, and to simultaneously compare findings across child population subgroups including age, race/ethnicity, health status, health insurance and family income groups
- Easy to understand quick guides to searching, downloading, saving and reporting results, and resource materials for learning about the content and methods of each survey
- “pop-up” boxes and tool tips that define terms and display the “recipe” for the derivation and construction of each indicator
- Fully cleaned and coded datasets and SAS and SPSS codebooks available for research purposes.
Who uses the DRC Data?

Academic and policy researchers, state and federal government, advocacy groups, community organizations, health care providers, students and parents all use the DRC. Since the public launch in 2004, the DRC website has received over 11 million hits and over 260,000 unique users. In the past three years 123 peer-reviewed and other public publications have cited the DRC as the source of data and/or technical assistance in the design and execution of research. The DRC provides routine and in-depth technical assistance in the effective use of the datasets by national, state, community and family constituencies; approximately 400 requests for such technical assistance are filled each year.

The pie chart to the right shows the national distribution of types of organizations requesting technical assistance with DRC data from 2006 to 2008 (N=1500). Oregon state data indicates a similar distribution.

What are they asking? DRC data is used for grant development, research, needs assessment & to engage partners in child & adolescent health issues.

Examples of Research & Policy Topics of DRC Users

- Primary care by type of insurance
- Overweight/Obesity research
- Title V Needs Assessment
- Impact of early intervention on ADD/ADHD
- Policy research on access to services for children with special health care needs
- Language barriers and developmental screening
- Advanced statistics course teaching aid
- Improving autism/autism spectrum disorder services grant
- Mental health services for children with special health care needs
- Child abuse prevention planning
- Family structure and childhood physical activity
- Health care quality and disparities
- After-school activities and children with special health care needs
- Breastfeeding and mental health
- Oral health and health insurance

Examples of Technical Assistance Questions

- Can I learn more about how the variable “at risk for developmental delay” was derived?
- Is there some way... that we can look at income effects on reading practices in CSHCN?
- How is medical home measured differently across the NS-CSHCN and NSCH?
- ...any way to get the ‘n’s’ for the parents that identified as foster mother and foster father in the survey?
- How have other medical home projects or organizations obtained parent input?
- I’m wondering if you can send me data on the percentage of families reporting access to transition services by income groups that match my state’s SCHIP eligibility levels?
- What are the figures for children with disabilities in Washington state?
- Is the entire dataset from the 2005/06 NS-CSHCN available in a format that could be downloaded & transferred onto STATA or SAS?
The CAHMI Program for Consumer-Centered Quality Measurement and Improvement

The CAHMI has a number of projects organized within its Program for Consumer-Centered Quality Measurement and Improvement. Key projects focus on new measurement development and validation, creating online data collection and reporting methods to assist pediatric practices with quality measurement and improvement, and the design and testing of patient-centered quality improvement tools.

Example Research Project: Practice-Based, Patient-Centered Quality Improvement Project

Early in 2008 the CAHMI was awarded a three year research grant from the Maternal and Child Health Bureau of the Health Resources and Services Administration to develop and evaluate the impact of patient-centered interventions to improve the quality and equity of recommended services for well-child care. The CAHMI collaborated with the Oregon Rural Practice-Based Research Network (ORPRN) and the Children’s Health Alliance in Portland to recruit three sites in the Portland metro area and rural Oregon for this developmental, proof of concept study. Each site will implement one of three interventions and will serve as its own control, using a quasi-experimental, pre and post intervention evaluation study design. The feasibility, acceptability and impact of the interventions on the quality and equity of well-child services will be evaluated with, among other tools, the Promoting Healthy Development Survey (PHDS) (see right) previously developed and validated by the CAHMI.

How have DRC Data been used in Oregon?

- The Oregon Developmental Disabilities Coalition used data from the DRC to write a Fact Sheet on expanding access to health care for children and their families. The Fact Sheet was provided to state legislators by family advocates.
- Dr. Brian Rogers, Director of OHSU’s Child Development and Rehabilitation Center (CDRC) used state-by-state comparisons from the National Survey of Children with Special Health Care Needs in his preparation for a legislative hearing on proposed budget cuts to the CDRC.
- The Oregon Developmental Disabilities Coalition used data from the DRC to write a Fact Sheet for state legislatures to encourage support of a Medicaid waiver for medically involved children. The one page document provides a quick overview that outlines facts and how the proposed legislation will benefit children and their families.
- DRC data on health indicators such as percent of low birth-weight babies, percent of high school dropout, high risk behaviors and prevalence of children with special health care needs was used to support arguments for new and improved statewide strategies and policies for an OHSU Pediatric Grand Rounds by Dr. Stacy Nicholson titled “State of the State: A Portrait of Children’s Health and Health Services Performance in Oregon.”
- In a June 2008 KATU news story titled “Oregon falling behind in children’s health care,” the CAHMI Director Christina Bethell used DRC data to illustrate the alarmingly high percentage of children lacking health insurance and preventive and dental care. KATU sent this data to the governor’s office, who responded by saying that it highlights the urgent need for Oregon lawmakers to expand children’s access to health care.

See other nationwide examples of data use of the NSCH and the NS-CSHCH!

Illustration of the CAHMI’s Online Portal for Parents to Complete the Promoting Healthy Development Survey. Responses are scored & reported back to both parents and their pediatric provider.
Jen DeVoe credits the experience of working with colleagues in the worlds of both academia and state government, and the opportunity to inhabit both worlds simultaneously during a joint appointment with OHSU and the state government, with her success at raising awareness about the real-world impact of health policy decisions on children. This impact was evident most recently in an article in JAMA titled *Uninsured Children with Insured Parents* that was presented at the National Press Club in Washington, D.C. and has generated more than 370 radio and TV broadcasts nationwide.

Dr. DeVoe received an MD in 1999 from Harvard Medical School and a DPhil in Comparative Health Policy from Oxford University in 2001, followed by a Family Medicine Residency at OHSU. In July 2004 she was awarded a two-year Agency for Healthcare Research and Quality (AHRQ)–funded fellowship that allowed her to pursue a joint appointment with the OHSU Department of Family Medicine and the Office for Oregon Health Policy and Research (OHPR). OHPR is, according to the website, “responsible for the development and analysis of health policy in Oregon and serves as the policymaking body for the Oregon Health Plan.” At the time Dr. DeVoe joined in 2004, OHPR researchers were in the midst of investigating the impact on adults of the 2003 cost containment changes to the Oregon Health Plan (the state Medicaid program) and were interested in expanding that research to children. As a family physician Dr. DeVoe was interested in studying children in the context of their families, and the convergence of investigators with policy and research backgrounds led to several important publications related to access to care for low-income families and children in Oregon. A 2006 AHRQ-funded K08 award allowed Dr. DeVoe to continue exploring the dynamics between health insurance coverage and access to care in the context of the family, both locally in Oregon and nationally using the Medical Expenditure Panel Survey (MEPS). A major finding, described first in Oregon and subsequently nationwide is the large number of uninsured children with at least one insured parent. The data show that low and middle-income parents with private insurance, usually through an employer, have the most difficulty keeping insurance coverage for their children. The parents often make too much to qualify for public health insurance, but are unable to pay private insurance premiums for the entire family. In the recent JAMA article cited earlier, DeVoe and colleagues found that approximately 3 million children (about 4% of children in the US) lacked continuous health coverage but had at least one insured parent; more than a third of these children were without coverage the entire year.

Dr. DeVoe and colleagues continue to collaborate on rigorous population-based research surrounding access to care for families; results will inform future health policy.
Rates of childhood obesity are climbing in the United States, disproportionately so among American Indian children. American Indian/Alaskan native (AI/AN) children have overweight rates that are 18-30% higher than the general American population of children. Childhood overweight can lead to an earlier onset of adult obesity and, subsequently, to a host of additional lifelong health problems, including cancer, Type 2 diabetes, heart attacks, and strokes, among many others.

Njeri Karanja, PhD, a senior investigator at the Kaiser Permanente Center for Health Research, has dedicated her research career to studying chronic disease prevention, specializing in nutrition and the health of minority populations. On the subject of childhood obesity, she believed in the importance of starting prevention efforts as early as possible. In 2001 the Portland Area Indian Health Board (NPAIHB) received a NIH grant to investigate community options to reduce the burden of disease among AI/AN. Dr. Karanja collaborated with Tam Lutz and other colleagues at NPAIHB to design and conduct a feasibility study called TOTS (Toddler Overweight and Teeth decay prevention Study). TOTS combined community-wide and family-based interventions to promote breastfeeding and reduce the consumption of sugar-sweetened beverages in American Indian communities, particularly among infants and toddlers.

The feasibility study was successful: the interventions resulted in increased breastfeeding initiation and duration; they also improved parents’ willingness to reduce sugar-sweetened beverage consumption. BMI rise slowed in American Indian/Alaskan native infants and toddlers.

Dr. Karanja’s interest in improving the health of Native American children prompted her to advance the TOTS findings. She and her NPAIHB colleagues received a larger grant in 2005 to test the effect of an expanded approach to preventing obesity beginning at birth. This new study is called PTOTS (Prevention of Toddler Overweight and Teeth Health Study), and its primary aim is to improve nutrition and physical activity in infants and toddlers using a combination of community- and family-based interventions. Nutrition goals include:

- increasing breastfeeding initiation and duration
- limiting sugared beverages for infants and toddlers
- improving parenting skills related to feeding behavior, specifically delaying introduction of solids until six months, promoting healthful choices when solids are introduced, and modeling eating behaviors.

PTOTS is also focused on physical activity goals that include:

- promoting motor development in infants
- reducing sedentary behavior, including limiting TV and video viewing
- creating play opportunities for infants and toddlers, including at least 30 minutes of structured play and 60 minutes of unstructured play daily.

PTOTS is underway, and results are expected in 2013. A birth cohort of about 600 children was randomized in six Pacific Northwest American Indian tribes. Three tribes are receiving a community-wide intervention with an added family component to alter the target behaviors, and three tribes are serving as a comparison group. Community Health Workers (CHWs) from tribal communities have been trained to use behavioral self-management principles and motivational interviewing to encourage participants to implement the study goals. In the community component, CHWs aim to 1) raise awareness, 2) deliver public health education to the community, 3) alter environments and policies associated with infant/toddler feeding and physical activity, 4) augment public health practice, and 5) change community and individual behavior.

CHWs are visiting families anywhere from 15 to 45 times over the duration of the study.

The primary outcome of PTOTS will be Body Mass Index (BMI) Z-scores at ages 24-30 months. Secondary outcomes will include: BMI at 0, 6, 12, and 18 months of age; breastfeeding initiation and duration rates; and survey data concerning parental knowledge, attitudes, beliefs, and practices about child feeding and physical activity.

PTOTS is breaking new ground in a number of ways: focusing on the very young child; using a comprehensive, multi-component intervention; intervening at multiple levels using the child’s ecology (the individual parent, the family network, and the community at large); and involving community members as interventionists, tailoring the intervention culturally to community and individual family needs.
**NEWS | EVENTS | HONORS**

**OCTRi and Child Health**

OCTRi is dedicated to the improvement of child health. In July 2008 OCTRI and the Department of Pediatrics joined Doernbecher Children’s Hospital and Foundation to open the Pediatric Clinical and Translational Research Center (PCTRC), which offers a dedicated inpatient and outpatient unit, RN study coordinators and Bionutrition Unit services. Contact the OCTRI Front Door to access the PCTRC.

In addition, OCTRI provides child health pilot project funding, is represented on the national CTSA Child Health Oversight Committee, and is committed to helping child health researchers in all phases of a research project. You can view a list of the child health and pediatric research projects supported by OCTRI resources on the OCTRI website.

**OCTRi e-newsletter**

The Oregon Clinical and Translational Research Institute produces a monthly e-newsletter with news related to clinical and translational research at OHSU, Kaiser Permanente Center for Health Research, and OCTRI’s other partner networks and organizations. View the last newsletter here. To receive future newsletters, please email octriadm@ohsu.edu.

**News**

- **Rich Mularski** is the 2008 recipient of The Roger C. Bone Advances in End-of-Life Care Award. The award recognizes physicians who have improved communication, compassion, and effective listening between themselves and their patients and families and support excellence in palliative and hospice care.
- The Mountain View Community Based Participatory Research Partnership in Madras, in collaboration with ORPRN, recently received funding from the Northwest Health Foundation for the “Policy Approach to Children’s Health” (PATCH) project. This 18-month project seeks to reduce childhood obesity by testing school-based policy issues.
- **Paul McGinnis** is Co-I (PI: Monica Hunsberger from OHSU Dietetics & Nutrition).
- OCTRI investigators **Patty Carney, LJ Fagnan** and **Cindy Morris** contributed to a successful CDC grant application submitted by the OR State Division of Public Health titled “Oregon Genomics Surveillance Program: Translation of Genomics Applications into Health Practice” (PI: Katherine Bradley, PhD, RN, Oregon Department of Human Resources) and will act as consultants on the study.
- As Maryland Komen for the Cure Affiliate visiting professor at the U. of Maryland, **Lillian Nail** discussed breast cancer survivorship research with nursing students and community members throughout the state.
- The Oregon Rural Practice-Based Research Network (ORPRN) is collaborating on a Pew Charitable Trust-funded study titled “Piloting Alternative Methods for Disseminating Evidence-Based Prescription Drug Information among Medicaid Providers in Rural Oregon ” (PI: Daniel Hartung, OSU College of Pharmacy)
- **ORPRN** (PI: Fagnan) and co-investigators Paul Gorman and Valerie King (OHSU) received funding from the Foundation for Informed Medical Decision-Making to develop and test models for implementing evidence-based patient decision aids into non-academic primary care practices (title: Shared Decision-Making in Primary Care). **Rick Deyo** will be a consultant.
- **Jackie Shannon** is PI on a new NCI grant to test the effectiveness of purified broccoli sprout supplementation intake in improving biomarkers for prognosis in patients with ductal carcinoma in situ and/or atypical ductal hyperplasia and in altering HDAC activity (title: Sulforaphane: A Dietary HDAC Inhibitor and Prevention of DCIS Progression).
NEWS | EVENTS | HONORS cont’d.

News, cont’d

- **Rich Mularski**, in collaboration with Dr. Jerry Krishnan at the University of Chicago, received AHRQ funding for a grant titled “Setting Effectiveness and Translational Research Priorities to Improve COPD Care”.
- **Greg Clarke** was awarded an NIMH grant for the development and piloting of CBT for insomnia in youth with comorbid depression.
- **LJ Fagnan** participated in a meeting convened by the leadership of the Oregon Pediatric Society to begin the process of aligning shared goals, vision, and necessary actions to achieve World Class Child Health in Oregon. The group generated a needs assessment and prioritized action points for moving forward. ORPRN was listed as an asset.
- Click [here](#) for the latest newsletter from the Oregon Rural Practice-Based Research Network (ORPRN)
- The East Linn Community Health Improvement Partnership recognized **Paul McGinnis** of ORPRN for his vision, leadership, and commitment to the organization since its creation 5 years ago.

Selected Publications by CPR Members

- **Rick Deyo** wrote a Q&A Column for Society of General Internal Medicine Newsletter on developing an early research career.
- **Mularski RA**. The search for a good death – are there quality insights accessible in medical records? Critical Care Medicine 2008;36(4):1372-1373.
- **Bunce AE**, Griest S, Howarth LC, Beemsterboer P, Cameron W, **Carney PA**. Educating Youth About Health and Science Using a Partnership Between an Academic Medical Center and Community-based Science Museum. Journal of Community Health (in press).
NEWS | EVENTS | HONORS cont’d.

Selected Publications, cont’d


Selected Presentations by CPR Members

- Rick Deyo gave a live webcast interview on self-care and treatment of back pain: Health Talk (Boston), [www.healthtalk.com](http://www.healthtalk.com)
- Rich Mularski was session chair of the ICU Pain Management Panel Discussion of the CCI/ACCP ICU Pain Group at the American College of Chest Physicians International Conference in Philadelphia, PA.
- Mark Spofford and Susan Chauvie discussed “OCHIN And Safety Net West: A Practice-based Research Network Partnership In Service to the Underserved” at the 5th Annual OCHIN Users Group, Portland, OR, November 20, 2008.
- Rich Mularski presented on “Pain control in the ICU” at The Harvard Critical Care and Trauma Symposium, in Boston, MA.
- Several CPR team members presented at the 36th North American Primary Care Research Group (NAPCRG) meeting in Puerto Rico, including: Unmet Dental Needs across the Lifespan in Rural Primary Care: A Clinic, Community, and Practice-based Research Network Collaborative (Davis, Fagnan, Hilton, Schott, Benson, McGinnis); Physical Disability and Preventive Services in Rural Primary Care (Buckley, Culley, Davis); and a workshop titled Aligning Experience, Expectations and Resources - PBRNs and CTSAs (Fagnan, Deyo, Davis, Werner, Stange).
- Evelyn Whitlock co-authored a presentation at the Medicare Evidence Development & Coverage Advisory Committee (MEDCAC) to consider national coverage related to CT colonography for colorectal cancer screening.
- Rick Deyo spoke on conflicts of interest in research to the Johns Hopkins CTSAs group.
- Paul McGinnis presented a seminar titled “Building a Medical Home Without Power Tools” at the AAFP Conference on Practice Improvement.
- Jackie Shannon gave a presentation on fatty acids, fatty acid synthase and prostate cancer incidence at the NW Prostate SPORE meeting.
- Rich Mularski gave a lecture on Quality Measurement & Innovation Tools to Improve Palliative Care Training and Implemented Skills at the ANTEA Worldwide Palliative Care Conference in Rome, Italy.
- Rich Mularski taught three sessions at the Dec 2008 KPNW Fundamental Critical Care Support course: Medical Ethics for Critical Care, Life-Threatening Infections, and Ventilator Management Practicum for the ICU.
- Rick Deyo gave an invited lecture at Dartmouth Medical center on "Lessons I’ve learned as a researcher trying to lead health care reform and how I learned them."