PS2-46:

Validity and Reliability of Health-related Quality of Life Instruments in Teens with Depression

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Background/Aims: Depression is one of the most common mental disorders among adolescents and is associated with substantial impairment, such as difficulties in school, interpersonal relationships problems, substance abuse, and suicide attempt. Understanding the impact of depression in youth and the effectiveness of interventions for this population requires assessments that capture the multiple domains affected by this disorder. In particular, brief measures that are easy to use are critical for research and practice for depressed teens. Brief health-related quality of life (HRQL) measures, which cover multiple life domains, may be one approach valuable for this purpose. In addition, use of generic HRQL measures allows decision-makers to compare the impact of depression to the impact of other health conditions in this population. However, few studies have examined the validity and reliability of HRQL measures in youth with depression. This study examined the validity and reliability of common HRQL measures in teens with and without depression. **Methods:** We interviewed 392 teens with and without depression using diagnostic instruments to determine depression status and seven common HRQL measures. We examined whether or not the HRQL instruments could distinguish between teens who were depressed and those who were not depressed, and whether they could distinguish different levels of severity of depression. We used multiple regression to control for demographic and other characteristics. In addition, interviewers provided qualitative assessment regarding whether or not the instruments seemed understandable and acceptable to teens. **Results:** Preliminary results indicate that all of the HRQL instruments evaluated were able to distinguish between youth without depression and those with depression. Four of the seven HRQL instruments were also able to distinguish between differing levels of severity of depression. **Conclusions:** This study provides one of the only reports of HRQL in teens with depression. Results of this study indicate that common, brief measures of HRQL do a good job distinguishing teens with and without depression. Results of this study can aid future research on HRQL in teens with depression by helping to guide which HRQL instruments are most useful in this population and the results also help to quantify the burden of depression in teens for policy

Keywords: Health related quality of life; Depression

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PS2-47:

Systematic Stakeholder Assessment to Determine Facilitators of and Barriers to SBIRT Implementation in Multiple Integrated Health Systems

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Background/Aims: The US Preventive Services Task Force has identified alcohol and drug use screening as a high priority in primary care. SBIRT is a framework for population based screening and brief intervention with the goal of reducing substance use before it progresses to dependence. There has been limited uptake of SBIRT in any large health system, thus SAMHSA has supported a series of studies, led by Kaiser Permanente Colorado (KPCO), to determine strategies to promote large scale SBIRT implementation. **Methods:** A qualitative examination of SBIRT feasibility and subsequent pilot testing within KPCO primary care guided a series of additional stakeholder interviews at Henry Ford Health System (HFHS) to assess feasibility of SBIRT implementation in additional organizations. Qualitative interviews were conducted with a broad spectrum of HFHS stakeholders using snowball sampling. A total of 28 HFHS stakeholders were interviewed. Interviews were conducted telephonically by trained interviewers from KPCO and lasted approximately 30 minutes. Interviews were digitally recorded and transcribed. After each interview, a detailed summary was generated and

used to create the initial code book for analysis of interview transcripts. **Results:** While current screening, brief intervention, and referral to treatment processes for substance use were noted in HFHS, they were inconsistent and no systematic policies exist. Many facilitators for SBIRT implementation within HFHS were noted including: population, recent implementation of depression screening in primary care, and EMR tools to facilitate documentation. Barriers to SBIRT implementation included time and competing demands for primary care providers, access to treatment, and follow-up processes for positive screens. All stakeholders were supportive of pilot implementation of SBIRT within HFHS with adequate attention to barriers and facilitators. **Conclusions:** This project successfully demonstrated the value of gaining stakeholder perspectives in order to facilitate successful implementation of SBIRT in large integrated health systems and provides a systematic protocol for gathering this data.

Keywords: SBIRT; Dissemination

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Patient Centered Outcomes Research/Member Engagement in Research

B3-1:

Developing a Protocol for Patient Engagement in Research: The HMORN Member Engagement Work Group

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Background/Aims: Integrated health care delivery systems are well positioned to engage patients in research due to their diverse patient populations. Managed care organizations cover 22.5% of the national population, making the establishment of a protocol for patient engagement in research in these settings particularly important. In 2012, researchers from the Institute for Health Research (IHR) identified resources and processes for patient engagement in the Kaiser Colorado region, and synthesized the findings in a Member Engagement Toolkit. After presenting this work at the 2013 HMORN conference the HMORN Member Engagement Workgroup [MEWG] was formed to compile current practices and identify priorities for further exploration. The MEWG aims to create a protocol and standards for member engagement in research and create instruments for measuring the success of engagement efforts in managed care settings. **Methods:** To do this we will conduct an environmental scan of engagement resources and processes currently available in the eight member organizations participating in the MEWG. We will use the IHR's Member Engagement Toolkit as a model to develop a patient engagement toolkit for HMORN organizations that will be generalizable to managed care settings nationally. Using the data from the environmental scan we will identify engagement methods, resources, policies, principles, and logistics for use by research teams embedded in managed care organizations. The scan will catalog best practices and gaps in engagement efforts that can inform the development of standards to guide engagement practices in managed care settings. We will conduct a targeted literature search and interviews with key informants to identify instruments for measuring success, and inform the development of instruments. **Results:** The MEWG will incorporate the findings from the environmental scan, a literature review and interviews with key informants into a toolkit, and present the results of the environmental scan at the 2014 meeting. Findings will also be available on the HMORN website. **Conclusions:** NA

Keywords: Patient engagement; Patient centered outcomes research (PCOR)

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B3-2:

Re-conceptualizing Medical Decisions: How Home Hospice Care Fosters Patient and Family Engagement and Decision-making

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Background/Aims: Despite growing acceptance that patient engagement and shared decision-making should be goals of medicine, organizational attempts to support these ideals are limited and larger institutional structures

often constrain patient autonomy. Home hospice care is a subset of medical care that has consciously developed a philosophical and practical approach to encouraging patient and family engagement. This research examines how home hospice care provides a different strategy for improving patient engagement and shared decision-making. **Methods:** This ethnographic study draws on a sample of 55 home hospice participants, including patients, family members/caregivers, staff, and volunteers, and uses in-depth interview and observation of home hospice work to examine the process of providing and receiving hospice care. **Results:** I find that macro level hospice institutional structures and micro level daily work practices embody a holistic approach which assumes patients and family members are the critical experts in most instances of decision-making. Differences in institutional structure, such as providing care in patient homes and having an interdisciplinary team approach focused on the “whole person”, empower the patient and family members. Likewise the micro level interactions between hospice workers and patients and family members narrow the field of purely “medical” decisions and broaden the field of decisions open to patients. Hospice workers accomplish this re-conceptualization by framing many medical decisions as being more about what is best for the patient and family and less about medical expertise. **Conclusions:** By broadening and re-conceptualizing the idea of decision-making, hospice workers enable patients and their families to have more control over their medical care and in many cases the process of dying itself. While some attributes of home hospice care are unique, many techniques could be introduced or accentuated in other models of medical care.

Keywords: Hospice; Decision-making

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B3-3:

PCORI's National Clinical Research Network

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Background/Aims: In September 2013 the Patient-Centered Outcomes Research Institute (PCORI) funded the National Clinical Research Network (NCRN) Coordinating Center (CC) to manage the development of PCORI's national data infrastructure to support patient-centered comparative effectiveness research. Initial NCRN membership will include 8 Clinical Data Research Networks (CDRNs) and up to 18 Patient Powered Research Networks (PPRNs). A number of HMORN members submitted CDRN applications. The CDRN and PPRN applications are under review to be announced in December. (Note: the HMORN authors of this abstract have no knowledge of nor will they participate in the CDRN / PPRN selection process). **Methods:** The NCRN CC is led by the Harvard Pilgrim Health Care Institute, and co-led by Group Health Research Institute, the Duke Translational Medical Institute, AcademyHealth, the Brookings Institution, the Center for Medical Technology Policy, the Center for Democracy & Technology, Johns Hopkins Berman Institute on Bioethics, and America's Health Insurance Plans. The RAND Corporation is the independent evaluator. The NCRN will organize its work around several taskforces, including: (a) Health systems interactions, led by Group Health Research Institute; (b) Creation of PCORInet, the networking capability to query NCRN partner data, led by Harvard Pilgrim Health Care Institute; (c) Governance, including how the NCRN will partner with external researchers to access the data infrastructure; and (d) Patient and stakeholder engagement, privacy, ethics and regulatory, rare disease and obesity cohorts, biorepositories, patient-reported outcomes and clinical trials. **Results:** PCORI's vision for the NCRN is to unite patients, healthcare systems and researchers to support rapid, effective observational and interventional studies of topics that are chosen by all stakeholders working in concert. We will describe the NCRN, the HMORN contribution to the Coordinating Center and, if applicable, will invite participation of HMORN members who are CDRN partners. **Conclusions:** The PCORI NCRN is advancing the nation's capacity to conduct comparative clinical effectiveness research by establishing an innovative and representative national research infrastructure. HMORN

investigators lead several aspects of this cutting-edge work.

Keywords: Patient-centered; Comparative effectiveness research

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B3-4:

Establishing an Aging-In-Place Model for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: Lessons Learned from a Community-research Partnership

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Background/Aims: Lesbian, Gay, Bisexual and Transgender (LGBT) seniors face barriers to accessing social services. We describe formation of an interdisciplinary community-research partnership called SUSTAIN (Seniors Using Supports To Age In Neighborhoods), whose ultimate goal is to develop and adapt an aging-in-place model in a Denver metropolitan neighborhood that is home to a high concentration of LGBT individuals. **Methods:** Established in 2009, SUSTAIN partners represent a cross-segment of service deliver, community building, education, and research interests including social service agencies; local LGBT community members; the Denver Gay, Lesbian, Bisexual, & Transgender Commission; a regional affiliate of Services and Advocacy for Gay, Lesbian, Bisexual, & Transgender Elders (SAGE); the LGBT community center for the state of Colorado; an affirming church leader; an area agency on aging; a non-profit healthcare and research organization; and a university researcher specializing in aging. Discussions were conducted among partners and written comments were solicited to understand community experience and reflections on the partnership. **Results:** The success of our SUSTAIN partnership hinged on several features. First, most partners' affiliations bridged at least two of the aging, LGBT, and research communities we were uniting. Second, the partnership development mechanism required at least fifty-percent of funds be allocated to community partners, which was crucial for establishing trust. Third, SUSTAIN's core values embraced a commitment to collaborative principles and explicitly addressed power imbalances. **Conclusions:** Members with existing capacity to connect communities and formalized funding frameworks that emphasize equity may be key ingredients for growing a sustainable community-research partnership.

Keywords: LGBT seniors; Community based participatory research (CBPR)

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PS1-23:

Prospective Association of Patient Activation Measure (PAM) with Medical Costs among Hypertension Population

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Background/Aims: The patient activation measure (PAM) refers to an individual's skills, knowledge, and confidence to manage their health and their ability to engage health providers in shared decision making practices. Such skills are important for the ongoing management of chronic conditions, such as hypertension. Although research has examined the association of PAM with utilization and health outcomes; little research has examined the association of PAM with medical costs. The objective of this research was to examine the prospective association of PAM with four cost measures: 1) total costs, 2) emergency department (ED) costs, 3) inpatient costs and 4) pharmacy costs. **Methods:** Using an observational study design, we studied 1,812 patients with hypertension with a PAM assessment between 12/4/2007 and 2/28/2011. The PAM is 13 items and categorizes PAM into four levels: PAM 1 (lowest level of activation, where patients typically lack confidence and self-management skills and may not understand the need to be actively involved in managing their health) and PAM 4 (highest activation where patients typically have the necessary self-management skills and are more pro-active about their health). Patients received care in Kaiser Permanente Northwest (KPNW) and were enrolled in care management programs. Per