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

patient per month (PPPM) medical costs were calculated 12 months after the PAM assessment date. Costs were constructed in 4 areas: total, ED, inpatient and pharmacy. Using Ordinary Least Squares Regression, each cost measure was regressed on PAM level (PAM 1 [reference group] vs. PAM 2, PAM 3, and PAM 4); adjusting for the following covariate measures; demographics and a severity of illness. We performed statistical analyses on logged PPPM medical costs, but report comparisons in absolute dollars (2011). **Results:** Compared to those with PAM 1 scores, those with PAM 3 scores had lower total costs (beta coefficient = - \$849; $P = .0004$), ED costs (beta coefficient = - \$22; $P = .02$) and inpatient costs (beta coefficient = - \$500; $P = .03$). **Conclusions:** Among a population with hypertension; adults with higher PAM scores (PAM 3) had significantly lower total costs, ED costs and inpatient costs, compared to patients with lower PAM scores (PAM 1).

Keywords: Patient activation; Medical costs

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PS1-38:

Building a Patient-centered Medical Home: Patient Perspectives from a Survey in an Integrated Healthcare System

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Background/Aims: As healthcare evolves to meet growing demand, it is crucial to maintain quality patient-centered care. In our quest to build a viable Patient-Centered Medical Home (PCMH) in our ambulatory care setting, we conducted this study to assess our patients' perspectives on patient-centeredness in our integrated healthcare system. **Methods:** Surveys were administered to all consenting English-speaking patients and accompanying relatives ages = 18 at 4 Family Medicine clinics. The questionnaire consisted primarily of Likert-type items with 5 choices ranging from strongly agree to strongly disagree on relationships within healthcare, communication with providers, access to providers, and coordination of care, along with basic demographics. **Results:** Of 316 patients approached, 204 (64.6%) returned completed surveys. Mean age was 47.4 (SD = 16.0; range 18-89); 67% were female, 84.4% white, 11.8% black, and 12.8% Hispanic. Majority were married (57.0%), employed (60.2%), had college education (69.4%), and reported an annual income of <\$60,000 (68.7%). The vast majority expressed believe that their healthcare team treats them with courtesy and respect (96.1%), trust their healthcare team with their medical care (93.6%), feel their healthcare provider communicates with them clearly using understandable language (95.6%) and listens to their questions, answering them directly (96%). Also the vast majority believe they play an active role in their healthcare (95.5%) and think it is important to be proactive in their healthcare (97%). Comparatively lower percentages of positive responses were noted when asked if the patient would like to use the Internet for filling prescriptions, making appointments, or communicating with their healthcare team (52%), if their provider inquires about their health goals (61.9%), and if their provider takes their health goals into account when developing a treatment plan (69.4%). **Conclusions:** In order to move towards a more PCMH, providers need to talk to patients about their health goals and incorporate them in developing a treatment plan. Since patients seem willing to take a proactive role in their healthcare and already trust their healthcare team, a PCMH model appears to be an attainable goal in our setting.

Keywords: Patient-centered medical home; Patient perspectives

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Statistical and Research Methods

B4-2:

Risk Engine Evaluation Software: An Analytics Platform for Individualized Guidelines

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Background/Aims: With the recent explosion of medical data, it is necessary to develop software tools to support the process of evidence review and synthesis that is fundamental to Evidence-Based Medicine. Furthermore, as predictive models are being increasingly integrated into clinical decision

making and personalized guidelines for individual patients, there is an even greater need for a practical tool that enables development, validation, and uncertainty quantification of models in a robust, automatic and efficient way.

Methods: We developed Risk Engine Evaluation Software, a software platform that enables users to compare and synthesize evidence from multiple data sources, to build robust and accurate predictive models to estimate and stratify disease risks, to validate risk equations and to quantify the accuracy of a predictive model in different subpopulations. **Results:** We applied the tool to data on cardiovascular outcomes from a large number of trials, observational studies and electronic medical records, including Framingham Heart Study, Atherosclerosis Risk in Communities Study, Cardiovascular Health Study, and ALLHAT. We demonstrated that users can evaluate the performance of predictive models for different subpopulations in real time. Several metrics were used for model evaluation: cumulative incidence, calibration plots, receiver operating curve (ROC) and net reclassification index. The software also allows users to generate and then assess models for risks of MI, stroke or heart failure, for a predefined subpopulation from selected datasets. **Conclusions:** Risk Engine Evaluation Software proves to be a useful tool for advancing the development and application of predictive modeling in medicine.

Keywords: Risk model; Individualized guidelines

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B4-3:

Is There Evidence of Non-response Bias for Survey-based Estimates of Urinary Incontinence?

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Background/Aims: Non-response is an important potential source of bias in survey research. It is usually difficult to obtain meaningful information on non-respondents to adequately assess bias on estimates of population statistics, especially when the survey involves sensitive or intrusive questions. We combined Electronic Health Record (EHR) and survey data to assess the impact of non-response on estimates of urinary incontinence (UI) prevalence. We used data from the baseline survey of the General Longitudinal Overactive Bladder Evaluation – Urinary Incontinence (GLOBE-UI), a population-based study of the natural history of UI in women = 40 years of age. We conducted the survey on a random sample of 7,125 Geisinger Clinic Primary Care patients. The response to the baseline survey was 57%. We also used electronic health records (EHR) data to obtain demographic, care utilization, health behavior, social history, and clinical information on all eligible respondents of the GLOBE-UI survey. **Methods:** We complete a two-stage model. First, we used logistic regression to assess baseline characteristics associated with response status. The predicted probabilities were used as a weight in the second stage model. UI status was defined for each response based on survey data. An Inverse Probability weighting (IPW) logistic regression model was applied to adjust non-response bias and to determine prevalence of UI based on baseline risk factors associated with UI status, including baseline characteristics, health utilizations, social and educational history, and comorbidities. The non-response adjusted estimate of prevalence was compared with prevalence obtained from respondents. **Results:** Age at survey, smoking, marital status, number of outpatient encounters per year, CHF, dementia, and severe liver disease were significantly associated with response status and UI status. Adjusting for non-response bias resulted in a reduction of the UI prevalence estimate from an observed value of 31% to an adjusted value of 28% for those 60 and older. The observed and adjusted estimates were not different for younger respondents. **Conclusions:** Non-response bias in women with UI is limited. It may lead to a marginal overestimate of UI prevalence for older patients. This could be explained by the non-response group being relatively younger.

Keywords: Non-response bias; IPW logistic regression model

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