Advances in the Use of Patient Reported Outcome Measures in Electronic Health Records

Including Case Studies

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EXECUTIVE SUMMARY

The goal of health care systems is to obtain optimal patient outcomes, decrease risk and disease, and improve or maintain functioning for individual and populations. Incorporating the patient perspective through patient reported outcome (PRO) measures is a crucial element for clinical care, quality performance management and clinical research. PROs are any report coming directly from patients regarding their health condition and treatment, including symptoms, functional status and health-related quality of life. Some PRO measures are generic and appropriate for use in a wide range of conditions, while others focus on the specific symptoms and side effects of a given disease, condition or treatment.

The use of PROs as outcome measures in research studies dates back to the 1980s. Since then, PRO data collection has increasingly integrated into health care. There is now a convergence in the evolution of PRO measurement, medical record keeping and comparative effectiveness research into an increasingly electronic and patient-centered space. Electronic health records (EHRs) began as an electronic version of the patient record for hospitals and clinics, and have evolved to serve a broader purpose of giving multiple stakeholders, including providers, managers and patients, access to a patient's medical information across different facilities. Systems have been developed recently that link EHRs to the collection of PRO data. One advantage of this linkage is that data collected for one purpose can potentially be used for multiple different tasks, including clinical care, quality assessment and improvement, research, and public reporting. Pilot studies, implementation efforts integrating PROs into EHRs and development of PRO research methods have received major federal support from the National Institutes of Health (NIH), Agency for Healthcare Research and Quality (AHRQ), Patient Centered Outcomes Research Institute (PCORI), Centers for Medicare and Medicaid Services (CMS), Food and Drug Administration, and the Office of the National Coordinator for Health Information Technology (ONC), as well as private and professional organizations.

PCORI has organized a National Workshop to Advance the Use of PRO Measures in Electronic Health Records (EHRs), to be held on November 19-20, 2013 in Atlanta, GA. This paper provides a landscape review of the current state of use of PRO measures in EHRs, focusing on themes in the implementation and integrations of PROs within EHRs.

We focused on PRO data collection systems that were linked to an EHR system. We did not include efforts to measure patient satisfaction independent of patient health status, electronic reviews of systems, family history, health behaviors or health care utilization.

The review includes 11 case studies from the US that illustrate the range of what has been done in diverse health care settings for clinical care, quality improvement and research. To supplement our review, we interviewed the principle developers and users of the systems. Many of the cases used the Epic Corporation EHR with its MyChart tethered patient portal for PRO data collection. The systems were based at Dartmouth-Hitchcock Medical Center, Cleveland Clinic, Group Health Cooperative, Cincinnati Children's Hospital, Kaiser Permanente Colorado (KPCO), Essentia Health/Minnesota Community Measurement, University of Pittsburgh Medical Center (UPMC), Duke University Medical Center, the University of California Los Angeles Medical Center (UCLA) and the University of Michigan Medical Center, and the University of Washington. The systems represent a broad range of functionality, patient populations and applications. Efforts at three health care plans (KPCO, Group Health and Essentia Health) illustrate applications of PRO collection at the plan level for clinical care, population based screening and quality of care evaluation. Hospital based efforts at Cincinnati Children's Hospital, the Cleveland Clinic and Dartmouth show how the use of PROs in specialty care can expand within a hospital. The review also includes examples of clinic-based, disease specific PRO collection (UCLA/Michigan's My GI Health, University of Washington Center for AIDS Research Networks of Clinical Systems (CNICS), Duke's Patient Care Monitor for cancer, and UPMC for primary care), some of which show how efforts may spread to specialists outside of the originating institution. While clinical care efforts focus primarily on providing the physician information to use during a patient visit, some systems also elicit information for follow-up evaluations. Essentia, through Minnesota Community Measurement, reports their scores as part of a statewide public reporting effort. A few organizations have integrated their systems into clinical and comparative effectiveness research (UCLA/Michigan, Cleveland Clinic, Cincinnati Children's, Duke), while others, like UPMC's system was designed to focus exclusively on clinical utility.

System features were examined across the 5 following categories: system design and implementation, measure selection, administration and data collection, reporting and interpretation, and analysis. While some of these system features are upstream from the technical aspects of EHR integration, each element builds the foundation for the focus, validity, interpretation and usefulness of the PRO data available in an EHR system. Overall the largest variations across these features were seen between systems that were designed using EHR-based PRO collection (e.g., Epic's MyChart feature) and outside collection that then sought to integrate information after collection and reporting. Systems that designed and collected PROs independently from the EHR, presented a much different approach allowing greater freedom in PRO content selection, more flexibility in patient access and score use, and limited ability to integrate PRO data with other clinical care markers. These trade-offs have implications at the person-, provider- and national-level which can be guided at this early point through standardization, developing a broad conceptual system architecture to encourage PRO collection compatible with larger research and evaluation efforts.

In our analysis, four major themes emerged regarding the integration and use of PROs in EHRs: (1) Necessity of System Customization, (2) Balancing Research and Practice Goals, (3) Demonstrating Value and (4) EHR Integration and Limitations. These themes were important considerations for all case studies leading to key decisions ranging from design (e.g., PRO content and selection) to intended use (e.g., clinical care, research or quality improvement). Systems did not necessarily make similar choices. For example the University of Washington chose to scale-up PRO collection to implement standardized PRO collection in a national research data network infrastructure, while Kaiser Permanente Colorado's effort has focused on patient screening and quality improvement. However each of these systems has considered these themes with respect to the feasibility to sustain and expanding PRO collection efforts into other patient populations and/or clinical settings.

There are a number of knowledge gaps identified in this report. These gaps center on the optimal system design features for PRO collection and integration. While these span PRO selection, administration analysis and security they all center around two main questions: the accuracy and accessibility of PRO data in an EHR. Ultimately these

current gaps point to the necessity of multidisciplinary teams and identifying “teachable moments” to educate clinicians, staff, researchers, and patients on PRO use.

There are a number of remaining barriers to sustainable PRO integration. These fall under three broad categories: patient, clinician, and system functionality. The most common barriers were related “hidden” elements linked to electronic PRO collection that are found even in the most developed systems. Regardless of the number of system features and staff expertise, system awareness, response rate, clinician use, and consistent system access (e.g., enough tablets available in clinic, Wi-Fi access) all rely on engagement from patients, clinicians, and staff. Fortunately, most barriers identified have been shown to be somewhat modifiable, with enablers that may be scalable.

To date, the perceived benefits of using PROs in clinical care have driven the implementation of in-clinic PRO data collection and EHR integration. Recent efforts to support PRO collection through patient portals offer a platform to further coordinate and develop PRO collection beyond the clinical encounter, further enhancing patient PRO monitoring for clinic, research and QI purposes. However, other options for collecting PROs are still necessary, including interactive voice response and in-clinic reporting. There is a diversity of approaches to PRO integration, and coordinated efforts are needed to increase the capacity to use them within EHRs for comparative effectiveness research. Barriers at the level of the patient, clinician and health system seem to be modifiable. There are considerable knowledge gaps regarding many scientific and practical aspects of implementing PRO measures into EHRs. Funding agencies and government bodies can support targeted research, infrastructure recommendations, education recommendations and methods development to help overcome current barriers, and ensure PROs can support the delivery high quality, patient centered care.

INTRODUCTION

The goal of health care systems is to obtain optimal patient health outcomes, decrease risk and disease, and improve or maintain functioning for individual people and populations, by efficiently delivering services of the highest quality – that is, services that are safe, timely, equitable, effective, efficient and patient centered (IOM 2001). Health care systems should learn from experience, by collecting and converting data about care and outcomes into knowledge. And such knowledge should be implemented into evidence-based clinical practice, driving improvements and the process of discovery as a natural outgrowth of patient care (IOM 2012). Health care choices made in collaboration between individual patients and their providers are central to this process. Incorporating the patient voice and perspective through patient reported outcomes (PRO) measures is critical for clinical care, quality performance management, and clinical research.

In recent years there has been a convergence of trends in the measurement of health, the evolution of medical records, and the development of comparative effectiveness research (Wu 2013). Figure 1 depicts the evolution and convergence these trends. The vertical axis indicates increasing patient-centeredness, and the horizontal axis indicates increased digitization. As the measurement of health outcomes has come to more consistently include the patient's own assessment of his or her overall health and well-being, the science of PRO assessment has advanced, and the electronic collection and storage of health data has become routine. Paper-based medical records have been converted into electronic health records (EHRs), which can include customizable, built-in or "tethered" patient portals. Comparative effectiveness research has become more patient centered, with increased emphasis on stakeholder participation and capturing the patient perspective on treatments and outcomes. Consequently, PROs, EHRs, and comparative effectiveness research have converged in an increasingly patient-centered and digital space, providing the opportunity for the routine implementation of clinical systems to collection patient-reported information.

PRO data collection is increasingly being integrated into health care. In the US, the National Institutes of Health, Agency for Healthcare Research and Quality, and Patient Centered Outcomes Research Institute (PCORI) have supported the development of

PRO methods for use in research and clinical practice (Lauer 2010, Wu 2010, Selby 2012). The Centers for Medicare and Medicaid Services and other payers, as well as the Food and Drug Administration, use PROs to evaluate interventions and programs(FDA 2009). The Office of the National Coordinator for Health Information Technology (ONC) has supported the use of PROs by allowing their use as evidence that providers are making “meaningful use” of EHRs to improve quality of care or patient centeredness, and are therefore eligible for incentive payments (What is Meaningful Use 2013). In 2012, the National Quality Forum, the American Medical Association-convened Physician Consortium for Performance Improvement (PCPI) and the American Society for Clinical Oncology all began initiatives to support the use of PRO measures for quality measurement and improvement (NQF 2012a,b; personal communication, email from Kristen McNiff, October 24, 2013). In September 2013, the Institute of Medicine formed a Committee for Social & Behavioral Domains in Electronic Health Records (The National Academies 2013) chaired by the Director of the NIH Office of Behavioral and Social Science Research and PRO expert, Robert Kaplan.

PCORI is organizing a National Workshop to Advance the Use of PRO measures in Electronic Health Records to be held on November 19-20, 2013 in Atlanta, Georgia. The workshop aims to review the current state of use of PROs in EHRs, identify barriers and facilitators to incorporating PRO measures in EHRs and identify specific actions PCORI and other organizations can take to support and promote the expanded use of PROs in EHRs.

In support of the meeting, this paper provides a landscape review (i.e., non-systematic review) of the current state of use of PRO measures in EHRs. The pragmatic, rather than comprehensive, nature of the review is necessary, as surprisingly little has been published to date on most of the leading systems to measure PROs in EHRs. The review includes descriptions of a broad range of initiatives currently underway across the health care system to integrate PROs with the EHR. The 11 case studies illustrate the feasibility of integrating PRO measurement systems in various clinical, health plan, and population-based settings, and the utility of using PROs across clinical care, quality improvement, and research settings. This review also discusses features of system design and highlights key elements central to integrating PROs in EHRs on a larger,

broader scale – including barriers, enabling factors and current knowledge gaps.

What is a Patient Reported Outcome (PRO)?

With the recent emphasis on patient-centered care and research (Selby 2012; IOM 2001, 2012), there is also increasing awareness of the importance of incorporating the patient's perspective in quality measurement and improvement. One approach for systematically capturing the patient's perspective is the routine collection of patient-reported outcomes (PROs). PROs are defined as any report coming directly from patients about their health condition and treatment (FDA 2009) and include a range of outcomes such as symptoms, functional status, and health-related quality-of-life (Acquadro 2003). Some PRO measures are "generic" and appropriate for use in a wide range of diseases, as well as healthy populations; other PRO measures focus on the symptoms and side effects of a given disease, condition or treatment (Patrick 1989). There is a long history of using PROs as outcome measures in research studies dating back to the 1980s (Tarlov 1989; Katz 1987; Lohr 1987; Lohr 1989; Lohr 1992; Lipscomb 2005; Brundage 2007; Bottomley 2007) and somewhat more recently, examples and investigations of using PROs for individual patient care (Nelson 1990; Wasson 1999; Meyer 1994; Greenhalgh 2009; Snyder 2009a; Greenhalgh 1999; Valderas 2008; Marshall 2006; Greenhalgh 2005; Aaronson 2011). A real advantage of PRO assessment is that the data collected for one purpose can be used in multiple different ways including clinical care, quality assessment, quality improvement, research and public reporting (Wu 2013).

Taxonomy of PROs

Greenhalgh (2009) proposed a taxonomy for the different applications of PROs in clinical practice. This taxonomy classifies whether the PRO data are used at the individual or aggregated-level and whether the PRO data are used directly or indirectly to inform patient care. For example, when an individual patient completes a PRO questionnaire and that patient's data are provided to his/her provider(s), the data can be used at the individual level to screen for clinical problems, monitor progress over time, or promote patient-clinician communication. If this information is aggregated across a group of patients (e.g., at the provider or clinic level, or for a subgroup of patients) this can be used to inform quality improvement or conduct population monitoring.

Model for Use of PROs for Clinical Care, Quality Improvement and Research

Complementing the Greenhalgh taxonomy, Snyder and Wu (Snyder 2013a) have proposed a model that describes the cycle of the use of PROs for quality assessment and improvement (Figure 2). This model demonstrates how the different aspects of the Greenhalgh taxonomy relate to each other, and can be used in a streamlined approach. For both the Greenhalgh taxonomy and the Snyder & Wu model, it is possible to implement either the full spectrum of applications, or one or more selected applications. Thus, there are a wide range of opportunities for using PROs in quality measurement and improvement.

For all applications, the cycle begins with assessing the PROs (Box 1). The assessments may come from a number of sources, including clinical practice applications, research studies and population surveys, as described in detail elsewhere (Snyder 2013b). When PROs are used for clinical practice, they are collected from a patient with the intention of informing his/her care and management. To date, the large majority of integration with EHRs has been done for this purpose. When captured in research settings, the most common use of PROs, it is usually as outcome measures in clinical trials and observational studies and often occurs outside of EHR systems. In this application, the primary purpose of the PROs is to describe the impact of various diseases and/or treatments on measures of health extending beyond clinical endpoints. Finally, PROs can be collected as part of population-based surveys that provide a patient-centered perspective to complement other statistics (e.g., mortality rates)(Barr 2003).

In many cases, there is the potential to use these PRO data, regardless of the original purpose for their collection, to evaluate the quality of care (Box 3). An example of this is the United Kingdom's National Health Service (NHS) Patient-Reported Outcome Measures (PROMS) initiative (http://www.hscic.gov.uk/catalogue/PUB11360). (NHS 2013). Specifically, the NHS is evaluating the quality of care for select surgical interventions, including hip replacement, knee replacement, varicose vein procedures, and groin hernias. Patients complete pre-procedure and post-procedure PROs, and these data provide insight into the patient-centered value of the procedures overall. For the period from April 2012 to March 2013, there were nearly 240,000 procedures for

which PRO surveys were to be collected. For the approximately 163,000 pre-procedures surveys returned, there were 88,000 post-operative questionnaires returned (NHS 2013). These surveys provide valuable insights into the impact of these surgical procedures on patient's functioning and well-being. For example, the proportion of patients reporting improvements on a general health status measure (the EQ-5D Index) ranged from 50% for groin hernia respondents to 87% for hip replacement respondents. The gains on the disease-specific measures were even greater, with 83% of varicose vein, 92% of knee replacement, and 95% of hip replacement patients reporting improvement. In addition to providing overall perspectives on the impact of these surgical procedures, there is also the opportunity to compare different hospital providers, though this may require case-mix adjustment (Devlin 2010). While the NHS example is one of the largest applications of PROs for quality measurement, other groups are also using, or planning to use, PROs in this way. For example, the American Society of Clinical Oncology is exploring the incorporation of PRO measures as quality indicators in its Quality Oncology Practice Initiative, focusing first on some common symptoms such as pain and nausea (personal communication, email from Kristen McNiff, October 24, 2013).

PROs may also be used for population health screening. In this application, PRO measures may be administered for disease screening, or for health risk assessment Nelson 2012). Disease screening programs can be used to identify untreated disease, such as depression in clinical care (American College of Surgeons 2011) or more broadly in the general population. Screening for health risks, for example, can be used to engage and motivate individuals to pursue changes in health behaviors, and the self-management of chronic conditions (Shekelle 2003). Health risk assessment can also be effective at inspiring the uptake of prevention and health promotion activities in employee health programs. Linking health promotion to health care visits and physician advice can potentiate the benefits of PRO screening.

While it is possible to go directly from PRO assessment (Box 1) to quality measurement (Box 3), an alternative approach would also use the data to improve the quality of individual patient management, as well (Box 2). The use of PROs in clinical practice involves having patients not only complete the questionnaires – but making an

individual patient's assessment available to the patient's provider(s) to inform that patient's care. Multiple systems have been developed for collecting PROs and using them for clinical practice (Jensen In Press, Bennett 2012, Rose 2009, Basch 2009). For example, at Johns Hopkins, we have developed the PatientViewpoint webtool that was linked to the institution's home-grown electronic medical record (www.PatientViewpoint.org) (Snyder 2009, Snyder 2012, Hughes 2012, http://www.youtube.com/watch?v=S-r4ykaUhfU). This tool enables clinicians to order PRO questionnaires much in the same way that they order lab tests or imaging studies. Patients receive an email when it is time to complete a questionnaire and the results are provided to both the patient and clinician. The use of PROs in clinical practice can improve patient-clinician communication, and can also have an effect on patient care and outcomes (Hayward 2006, Valderas 2008, Marshall 2006, Greenhalgh 1999, Greenhalgh 2005, Velikova 2004, Velikova 2010, Berry 2011, Santana 2010, Detmar 2002, Bliven 2001, Boyce 2013, Espallargues 2000, Gutteling 2008, Lyndon 2011, Taenzer 2000, Takeuchi 2011) Thus, the PRO collection in itself can be an intervention with the intention of improving individual-level patient care.

As noted above, using PRO data for individual patient care in no way precludes using the data for quality measurement. In fact, it facilitates the process if collected in a systematic way. It is feasible to take some or all of the individual patient's PRO assessments and aggregate them to summarize the patterns and quality of care received at the clinic or health plan level (Box 3). Examples of this might be for pay-for-performance, or for pubic report cards.

The next step in the process is to use the PRO data to inform quality improvement (Box 4). Dr. John Browne from University College – Cork has described how this process works using the example of breast reconstruction following mastectomy (Browne 2009). In Browne's example, individual surgeons are presented with the average PRO scores of their reconstruction patients. The surgeons' performance falls into a distribution, with some surgeons' patients reporting lower PRO scores and other surgeons' patients reporting higher PRO scores, on average. While PRO measures provide some indication of relative performance, scores alone are not particularly illuminating in terms of how to improve care. The key is to be able to translate the scores into descriptive

labels that can inform patient management. In Browne's example, lower scores reflect women who find their breasts' shape to be acceptable when clothed; the average scores reflect women reporting that their breasts 'line up' when unclothed; and the highest scores represent women who report that their breasts are equal in size and shape when unclothed. These descriptive labels can inform a lower-performing surgeon regarding what areas require increased attention, making the PROs a powerful tool for quality improvement.

The cycle then begins again with PRO assessment (Box 1) – ideally, with the PRO scores demonstrating the improvements based on the applications of the PRO data for quality assessment and improvement (Boxes 2-4). In addition, having accumulated a number of PRO reports creates another opportunity for using the PROs in clinical practice (Box 2). That is, group-level PRO data can be assembled in the form of decision aids that can be used to explain the implications of treatment alternatives and help patients and clinicians decide on the appropriate strategy for a given patient. In contrast to the use of an individual's PROs informing his or her care, in this application, PRO data from other patients are summarized and presented to a patient to help him/her understand other patients' experiences with the various treatment options. For example, Brundage et al. have shown that lung cancer patients presented with the hypothetical option of chemotherapy used information regarding the impact of chemotherapy on survival, toxicity as well as on health-related quality of life to inform their decision (Brundage 2005). Thus, as more data are collected about patient experiences using PROs, more patients can benefit from a clearer understanding of the quality-of-life implications of different treatment options. This cycle is exemplary of the functioning of a learning health care system – one in which best practices are embedded in the delivery process and new knowledge is captured as an integral byproduct of the delivery experience (Olsen 2007).

While the above discussion of the applications for PROs in quality measurement and improvement around the cycle focuses primarily on the PROs themselves, the power of PROs increases substantially when the PRO data are linked with other clinical information (Wu 1997, Snyder 2013b). Linkage to treatments and clinical events can provide information about treatment effectiveness for individual patients, while linkage to

patient and disease and provider characteristics can help to generate evidence about the effectiveness of the care delivered by providers. The integration of PROs in EHRs offers great potential in terms of applying PROs during each phase of the cycle. Below, we provide additional background on EHRs and then describe how PROs, combined with the EHR data, create valuable opportunities for patient-centered care and research.

Electronic Health Records (EHRs)

A more detailed review of EHRs is beyond the scope of this paper. The following is a brief history of the development of the electronic health record and a description of its current state. An EHR can be defined as a systematic collection of electronic health information in digital format about individual patients or populations. Data may be captured in many ways, including as structured data that can be subjected to immediate analysis and other ways such as free text or images. Information is stored so that it can be accessed across different health care settings including hospitals, clinics and other care facilities, and even by individual patients. EHRs can collect a broad range of data, including patient demographics, medical and social history, medication and allergies, diagnoses and problems, immunization status, laboratory and other test results, vital signs, physical examination findings, billing information and various documents. Additional functions include the ability to execute orders for tests and medications, schedule future appointments, generate referrals to other providers, track care and outcomes, trigger warnings and file public health reports. Information within an EHR can be used for secondary analyses for research, quality assessment, quality improvement and reporting (Weiner 2012).

The acronyms EHR and EMR (electronic medical record) are often used interchangeably. An EMR denotes an electronic version of the patient record created for hospitals and clinics whereas an EHR has a broader purpose of giving access to a patient's medical information to multiple stakeholders across different facilities within and institution or network, including patients, health care providers, managers, payers, insurers, and employers.

The modern medical record dates back to the 1970s when records were still maintained exclusively on paper (Weed 1972). There were a few initial attempts to digitize these

records and provide computerized decision support (NIH 2006). Electronic medical records began to be developed in the 1980s for administrative purposes. A notable effort was the Veterans Administration's VisTA which was adopted universally across VA Medical Centers (Brown 2003). In the 1990s the first Windows-based medical records were released (NIH 2006). The scope of EMRs broadened in the early 2000s to include a range of non-clinical health information, leading to the term "electronic health record". Some of these EHRs have integrated patient portals and allowed patients to communicate securely with health providers and to enter additional information. The process was greatly accelerated by passage of the Health Information Technology for Economic and Clinical Health Act and availability of stimulus funds to reward the "meaningful use" of data by adopters of EHR (ONC 2012). A move to develop standalone personal health records was also initiated (Tang 2006), which is proceeding with increasing success but will not be reviewed here.

As these systems have developed, EHR-based patient portals (referred to as tethered portals) have emerged as the most prevalent structure. These portals permit patients to retrieve their records and to enter additional information (Tang 2006). It is uncertain what proportion of EHRs have the capacity to collect PROs. A number of standalone web tools have been designed specifically to capture and report PRO measures, in part in response to the lack of availability of this capability within existing EHRs. Most of these do not interface directly with EHRs. Other example as mentioned above is PatientViewpoint, developed by our group (which does link to the EHR), with other examples of integrated systems identified in the case studies section (Snyder 2009, Snyder 2012).

EHRs systems have the potential to enhance patient-clinician interactions through the incorporation of patient-level PRO scores. In some EHRs, clinicians can access reference materials to support decision-making. Other systems have automated alerts and decision support that is built-in to help guide practice precisely when it is needed.

Today, over 57% of office-based physicians use EHRs (Hsiao 2011). Concurrently, despite worries about a potential "digital divide" exacerbating existing disparities in care, internet use is increasingly prevalent for both genders and all age groups, races/ethnicities and income levels. This advance is due in part to internet access from

laptops, tablets, telephones and other handheld devices (Zickuhr 2012).

We are now in the midst of a period of rapid development of EHRs capabilities alongside an even more rapid proliferation of web-based options for PRO collection. A natural place for these data to go is into EHRs, but there is relatively little published on the best practices and new developments in linking PRO data collection to the EHR. For that reason, we undertook a search of the published and grey literature on the current state of use of PRO measures in electronic health records. We were interested in identifying highly developed and innovative systems for PRO data collection that feature EHR integration. We were also interested in common themes in the implementation and integration of PROs within the EHR, including barriers and facilitating factors, and in identifying key unanswered questions important to the future on PRO measure integration in the EHR.

METHODS

We conducted a landscape (non-systematic) review to identify existing and leading systems that collect PROs and link to EHRs. We were interested in systems that were used in clinical practice. Systems were eligible if they are used in clinical care settings, assess PROs electronically and provide summaries of the patients' response to providers.

Systems were identified through publications, as well as conference abstracts, white papers, reports published online or in print and other grey literature. The latter included information from unpublished presentations, publications and news reports. We obtained additional detail through interviews with key informants identified by the Planning Committee and our own network of colleagues and collaborators. PubMed, MEDLINE and Embase searches used the following terms: [patient-reported outcomes (outcome assessment, quality of life, health status indicators, patient-reported), and clinical care (patient care, clinical care, delivery of health care)]. We excluded PRO data collection systems intended exclusively for clinical trials. We also excluded electronic PRO data collection systems that were not linked to EHRs. This exclusion category included some major PRO reporting efforts (Meyer 1994, Gustafson 2001, Wasson 1999, http://www.howsyourhealth.org/, Cohen 2013), but allowed this report to

specifically focus on how PRO data is integrated with EHR information. In addition, we did not include the large number of efforts to measure patient satisfaction independent of PRO measures of health status. We did not include the many other different kinds of health related information, including the review of systems, family history, health behaviors such as tobacco or alcohol use, and health care utilization.

We limited our selection of case studies to US systems (Table 1) although there are important international efforts of note (Gilbert 2012, Dudgeon 2012, Black 2013, Varagunam 2013; Bainbridge 2011, Engelen 2010). The cases we present do not represent the full range of systems. While PRO collection and integration are most common in specific clinical populations such as cancer, rheumatology and orthopedics, we selected systems that represent a range of applications from the general population to specific disease conditions. We included cases used in health systems with different payment and organizational models and different scale from small to large. For each case study, system characteristics and clinical implementation were identified and abstracted using a structured review form created by the authors. We supplemented the reviews with interviews with the principal system developers and users. The summary extract of information was verified with the system developers from whom we also obtained follow-up information when necessary. Table 1 summarizes the 11 case studies, including their system affiliation and name, the initial clinical population, and whether they are used at multiple practice locations and for multiple patient populations.

TABLE 1: SUMMARY OF CASE STUDIES

#	System Affiliation (Name)	Initial Population	Multiple Sites/Clinics	Multiple Populations
1	Epic Systems Corporation (MyChart, EpicCare)	Epic Users	Y	Y
3	Cleveland Clinic (Knowledge Program)	Neurological Disorders	Y	Y
2	Dartmouth Spine Center	Spine	Y	Y
4	Group Health Cooperative (Health Profile e-HRA)	General	Y	N
5	Cincinnati Children's Hospital	Rheumatology	Y	Y
6	Kaiser Permanante Colorado (PATHWAAY)	Older Adults	Y	N
7	Essentia Health (MN Community Measurement)	Depression	Y	N
8	University of Pittsburgh Medical Center	Primary Care	Y	Y
9	Duke University (Patient Care Monitor)	Cancer	Y	Y
10	UCLA/Michigan (My GI-Health)	GI Disorders	Y	N
11	University of Washington/ Centers for AIDS Research Networks of Clinical Systems	HIV	Y	N

For each case, the first page provides an overview of the system and its development, including conditions and PROs included; the nature of integration of PRO measures within the EHR, applications in clinical practice, research and quality improvement, and future plans for the system. The facing page shows a graphic example of one aspect of the system, a walk-through of the process of patient assessment and data flow, key themes highlighted by the case, and data sources.

Epic Systems Corporation MyChart

Basic System Summary:

MyChart (Epic Systems Corporation, Verona, WI) is a secure member website through which registered patients can view portions of their medical record and exchange secure messages with physicians. Although collection of PROs within Epic had been implemented prior to the 2012 release of MyChart, the release of the "series" feature for PRO ordering and "definition" tool added features that added value for researchers. Epic has been granted permission to provide the following PRO measures as part of their Foundation System. They are:

Measure	Dimensions
Medical Outcomes Study	SF-20 (20 item Short Form health survey), RAND-36
PHQ2/PHQ9	Depression
PROMIS	
Adult (18 years and greater) static short forms	Physical Functioning (10 items); Pain Interference (8 items); Global Rating of Pain (1 item); Sleep Disturbance (8 items); Fatigue (8 items); Depression (8 items); Anxiety (8 items); Satisfaction with Participation in Social Roles (8 items)
Pediatric Self Report (8-17 years) static short forms	Physical Functioning--Mobility (8 items); Pain Interference (8 items); Global Rating of Pain (1 item); Fatigue (10 items); Depressive Symptoms (8 items); Anxiety (8 items); Peer Relationships (8 items)
Proxy (5-17 years) static short forms	Physical Functioning--Mobility (8 items); Pain Interference (8 items); Global Rating of Pain (1 item); Fatigue (10 items); Depressive Symptoms (8 items); Anxiety (8 items); Peer Relationships (8 items)

EHR Integration:

Complete integration with the Epic EHR. PRO scores can be viewed and manipulated alongside other clinical data elements such as laboratory test results.

Clinical Practice:

Epic 'series' definition functionality makes it possible on an individual or sub-population basis (e.g., all patients age $\geq$ 65) to specify the timings and intervals of automated releases of one or more PRO measures. Organizations can build additional EpicCare/MyChart questionnaires

Research-Related:

It is possible to specify the timing and intervals of automated releases of PRO assessments. PRO data are aggregated across patients in Epic's analytic environments (Cogito Clarity and Cogito Data Warehouse) with common data structures across organizations.

Quality Improvement:

Organizations that have implemented Clarity and/or the data warehouse are able to develop reports that include PRO data.

Future Plans:

Long-term plans are to expand to additional PROs in their Foundation system.

Epic Systems Corporation: EpicCare longitudinal integration of PRO and clinical data

Walk-through of the Patient Assessment Process

A provider working within the EpicCare EHR orders one or more PROs to be completed by the patient. The patient receives secure email notification via the MyChart patient portal and completes the PRO assessment online. The results are released immediately to the EpicCare EHR where they can be viewed by the provider alongside other test results**.**

Key Themes

- Completed via tethered patient portal MyChart
- Fully integrated within Epic ecosystem including EpicCare EHR. PRO data are aggregated across patients in Epic's analytic environments (Cogito Clarity and Cogito Data Warehouse)
- Foundation system includes pre-specified PRO measures
- New PRO measures require Epic trained programmers to implement within MyChart

Sources: Unpublished presentations, discussion and email communication (Nancy Smider)

Cleveland Clinic Knowledge Program

Basic System Summary

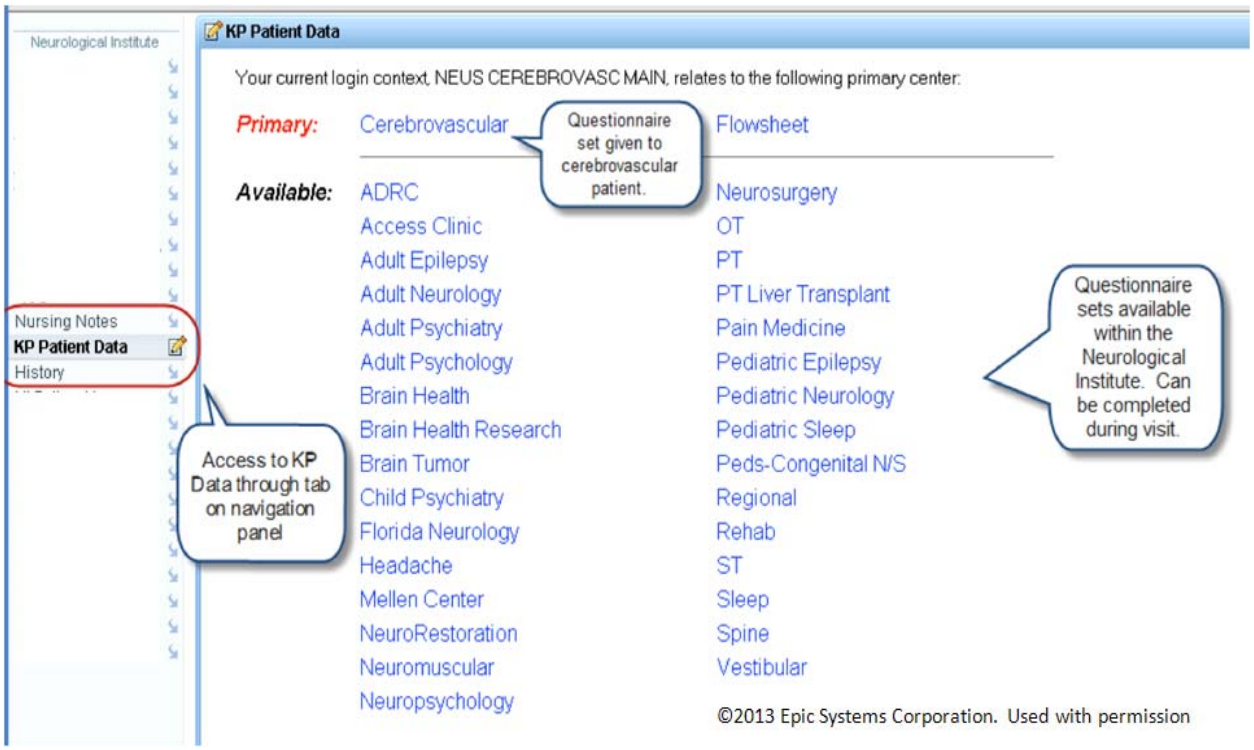
The Knowledge Program (KP) is a data collection system and repository designed to enhance electronic clinical data, including the addition of PROs. Goals were to help guide care, to link to CarePaths (CP) to standardize management of specific conditions and to increase the ability to extract data from the EHR for secondary use. KP was developed in 2007 by the Neurological Institute (NI) of the Cleveland Clinic in collaboration with the Imaging Institute and IT Division. All departments in the institute started simultaneously in a "Big Bang." KP uses both standard PRO measures and custom questionnaires, which can be built quickly using a content manager tool. Conditional flows of questions can be built in. There are provider questions to create metadata, e.g., why the patient did not complete a PRO or date of a clinical event. A KP query tool can extract different kinds of data for secondary use. Most patients surveyed thought the data were useful (especially if the provider reviewed results with the patient) and questionnaires were not too long. Completion rates are >80%. The majority of providers surveyed also reported that PRO data were useful. KP now includes all of orthopedic spine surgery, cardiology, gastroenterology, head & neck, and plastic surgery. In addition to the standard EQ-5D and PHQ-9, KP also collects the PDQ, a Pain scale, Central Sensitization Inventory, Modified JOA (neck or cervical myelopathy) and questions on days missed and work status, for a total of 164 PROs or ClinROs.

EHR Integration: Survey build and data collection are done outside of the Epic environment, but reports are viewable in EpicCare. Office-based collection of data via tablets goes to a custom "NI health status" tab in the Epic navigation panel. The provider display comprises screen shots, flow sheets and text and cannot be manipulated within Epic. NI has encouraged use of MyChart for PRO data collection prior to an ambulatory visit – MyChart now comprises up to 23% of PROs completed.

Clinical Practice: A total of over 961,000 patient visits to 1,062 providers; There are more than 330,000 individual patients with PRO data since 2007. Scores can be tracked over time within KP. Neurologists have found PHQ9 helpful. A best practice alert (BPA) was set for a score greater than 15; an order set pops up with recommendations for antidepressants, referral to behavioral health specialists, and patient education.

Research: In neurology, PROs are used in clinical research to track response by disease and type of patient, and how depression affects management and outcomes for specific conditions. Ortho/spine finds KP to be very useful, with 3-4 of their faculty doing exclusively outcomes research. There are some frustrations with missing data and follow-up. Many current studies are ongoing including: CER, e.g., in degenerative spondylolithesis, radiculopathy treatment; Methodologic: e.g., responsiveness of mJOA score to improved QOL; Clinical, e.g., the effect of obesity on patient outcomes; Health services research: cost of surgery vs outcome; outcomes for 8 different surgeons (Gross 2013; Gogawala 2011, Conway 2012; Su 2012, Jehi 2011).

Cleveland Clinic Knowledge Program: PRO measure sets available in EpicCare



Walk-through of the Patient Assessment Process

Data collection is currently mostly on tablets which are given to patients in the office waiting room when they arrive to register. Kiosks and increasingly MyChart (over 20% of all PROs completed in 2012) are also used for data capture. The data go into the KP databases and can also be seen by providers on a "KP Patient Data" tab in the Epic navigation panel. A KP tool allows data extraction for research and quality improvement.

Key themes

- Initially built around neurological disease. Goals included individual patient care, quality of care, research and policy/reimbursement (demonstrating outcomes needed to show value)
- Large number of standard and custom PROs (and some ClinROs: a total of 164 patient or provider questionnaires)
- Initially tablet computer entry, now increased proportion via MyChart with integration with EpicCare EHR
- Important enablers: leadership support, effort was clinically driven, allowing individualized questionnaires, availability of metrics on completion and use, integration of technical and clinical teams
- Barriers: dedicated resources are needed to analyze and report PRO results

Sources: KP webinar August 7, 2013; discussion (Irene Katzan, Ajit Krishnaney, Eric Mayer); Katzan 2011 a,b; Katzan 2012; Atreja 2012; Gurland 2010).

Dartmouth Spine Center

Basic System Summary:
The Dartmouth system is a PRO data collection system integrated within the Epic EHR. The Center began PRO data collection efforts in 1998, based at the Dartmouth Hitchcock Medical Center in Lebanon, NH, led by Dr. James Weinstein (Weinstein 2000). The collection of structured PRO data before each visit was a fundamental process for the achievement of care planning, shared decision making, monitoring individual impact of treatment and quality improvement, research, and public reporting. In 2005 Dartmouth partnered with Dynamic Clinical Systems to collect PRO measures, interfacing with their home grown EMR. At the time, reports were visible in the EMR as blocks of text. The initial driving force came in part from early adopters who already believed in the value of PROs. Every condition had a local physician champion and selection of PROs came about from extended conversations among a multidisciplinary team. In April 2011, Dartmouth transitioned to Epic and the decision was made to do as much as possible within Epic to minimize interfaces. Dartmouth is currently collecting PROs within 12+ clinical programs (Ortho, Plastics, Spine, Pain, Heme/Onc, Psychiatry, OB/GYN, Rehab, Neurology, Primary Care, Surgery/Anesthesia, Vascular) and 25+ different health conditions (Hip/Knee/Shoulder; Hand/Breast; Breast, Head & Neck, Neuro and Prostate Cancer; Sleep, Depression, Anxiety; Epilepsy/MS). PRO measures include PROMIS, VR 12, PHQ-9, condition specific instruments, a risk assessment tool, alcohol screening, and many custom questionnaires (e.g. Review of Systems, ADLs). Baseline collection rate is >80% but is more limited for follow-up data.

EHR Integration:
Data collection is either via MyChart or Welcome tablets/kiosks in the office and is fully integrated in EpicCare EMR. Foundation PRO measures are entered as discrete data and can be manipulated in Epic. The care team can review results immediately in chart review or visit navigator.

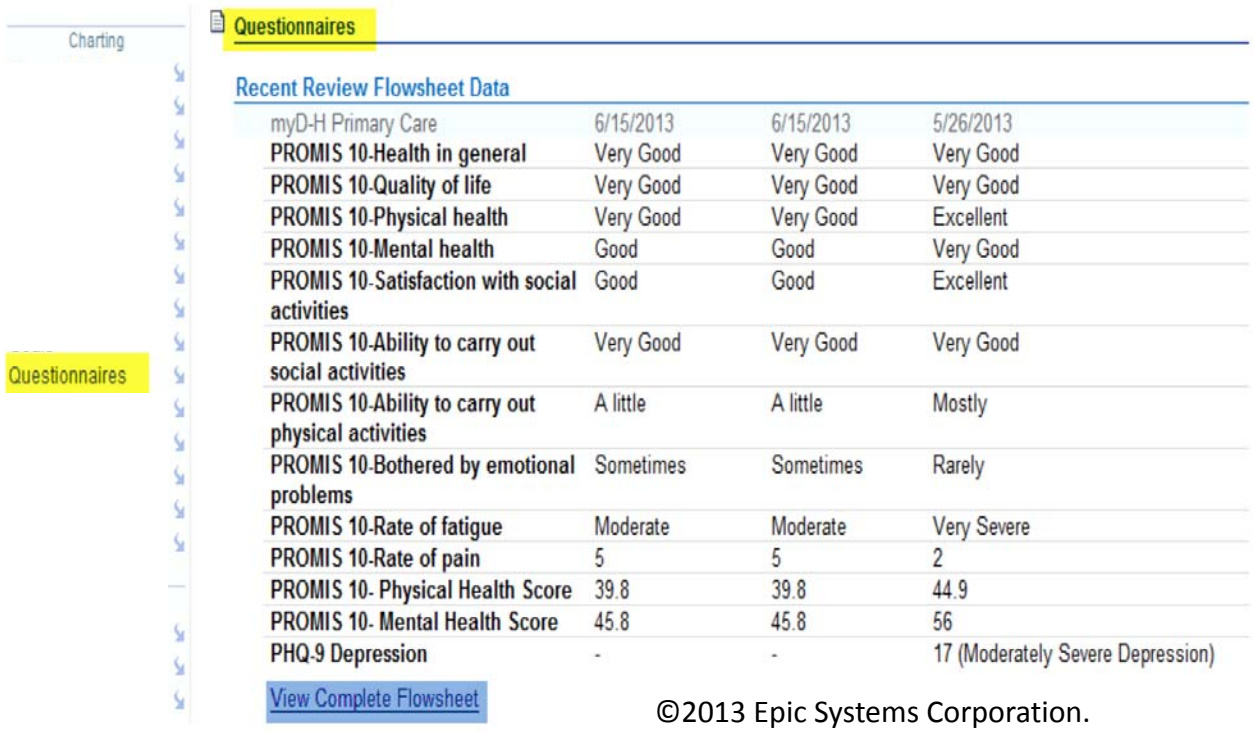
Clinical Practice:
All electronic communication is via a secure patient portal. Summary reports are generated from PRO data for making and monitoring the care plan. A survey of spine patients (Hvitfeldt 2009) found that 80% rated the system excellent to good and 1/3 reported that PROs had led to positive changes in their visit (pre EPIC implementation). Clinicians reported that PRO measurement systems were important for follow up and feedback but expressed mixed views on whether it saved or added time to the visit. Alerts are set up for patient reports of suicidal ideation.

Research-Related:
PROs are used in practice-based research. Research consent forms are programmed like other questions into the system. The Spine Outcomes Research Trial (SPORT) has followed thousands of patients in 13 centers for >5 years, with most of the primary results based on PRO data (Weinstein 2006, 2007).

Quality Improvement:
Data are used for program performance and improvement, and are reported on the Dartmouth public website.

Future Plans:
Long-term goals are to improve the ability of clinicians to order PROs, to increase the customization of clinical reports, and to improve score interpretation for patients and clinicians. Additional goals are to improve compliance with follow-up PRO data collection and system capabilities to extract population data for quality improvement and research.

Dartmouth Spine Center: PRO domains flowsheet data in EpicCare



myD-H Primary Care	6/15/2013	6/15/2013	5/26/2013
PROMIS 10-Health in general	Very Good	Very Good	Very Good
PROMIS 10-Quality of life	Very Good	Very Good	Very Good
PROMIS 10-Physical health	Very Good	Very Good	Excellent
PROMIS 10-Mental health	Good	Good	Very Good
PROMIS 10-Satisfaction with social activities	Good	Good	Excellent
PROMIS 10-Ability to carry out social activities	Very Good	Very Good	Very Good
PROMIS 10-Ability to carry out physical activities	A little	A little	Mostly
PROMIS 10-Bothered by emotional problems	Sometimes	Sometimes	Rarely
PROMIS 10-Rate of fatigue	Moderate	Moderate	Very Severe
PROMIS 10-Rate of pain	5	5	2
PROMIS 10- Physical Health Score	39.8	39.8	44.9
PROMIS 10- Mental Health Score	45.8	45.8	56
PHQ-9 Depression	-	-	17 (Moderately Severe Depression)

Walk-through of the Patient Assessment Process

When a new patient or an annual visit is scheduled the scheduling system follows rules to order appropriate PRO measures that are tied to the upcoming appointment. If the patient is active on MyChart, s/he gets appointment and questionnaire reminders. If not, or if the patient does not fill out the questionnaire through MyChart, the patient receives a tablet at check in and completes PROs in the waiting or exam room. When the patient sees the clinician they review current and trended data. The clinician charts core/meta data on the patient. The warehouse receives, stores, manages, and analyzes data from multiple sources including diagnostic tests and claims. The warehouse distributes reports for individual patients, clinical populations, quality measures, and research. The next release of Epic will allow series of PROs to be ordered.

Key themes

- Initially built for spine surgery, vision was importance of the patient perspective, collecting information at point of care, simultaneously built into research.
- PROs for 12 different clinical programs and 25 different health conditions.
- Initially based on Dynamic Clinical Systems for PRO data collection and home grown EMR, switched in 2011 to Epic and MyChart with some losses and gains in functionality.
- Important enablers: support from top clinicians and leaders and enthusiasts; effort was clinically driven
- Barriers: Epic lacks easily accessible features to customize clinical reports. It has taken significant resources and expertise to get a standard report on questionnaire completion rates.

Sources: KP webinar October 30, 2013; discussion (Carolyn Kerrigan); Nelson 2012

Group Health Cooperative Health Profile (Health Risk Assessment)

Basic System Summary

The Health Profile is an electronic Health Risk Assessment (e-HRA) that targets adults and is integrated with the EpicCare electronic record at Group Health Cooperative, a large health plan in Washington State. The overall goal is to provide advice to patients and their providers based on information entered by patients via the patient portal (MyGroupHealth) that is integrate in the EHR. In 2006, Group Health developed the interactive online e-HRA that collects information from members, integrates it with other EHR data and produces individualized health improvement recommendations. The recommendations align with Group Health's clinical practice guidelines. The goal is to promote prevention and health promotion behaviors through patient interaction with their Health Profile. Preventive health behaviors are reinforced by clinicians since the recommendations align with Group Health clinical practice guidelines. Data are also used for quality improvement. PRO measures are part the e-HRA, including functional health status, health-related quality of life, and the PHQ-2. The questionnaire takes approximately 20 minutes to complete and incorporates branching logic and algorithms. Health Profile data appear in EpicCare as structured data, free text and reports. Past reports are archived and can be reviewed. Messages are triggered if an urgent need is identified. There is a paper-based alternative that is not linked to the EHR.

EHR Integration:

Data collected via MyGroupHealth flow as reports into EpicCare. There is 70% uptake of MyGroupHealth. These are structured data elements that cannot be manipulated within Epic. Data are summarized in recommendations to be reviewed by the patient and clinicians.

Clinical Practice:

Design of the system was driven largely by clinicians and executed by an integrated multidisciplinary team. Selection of instruments, risk calculation and recommendations are evidence based so they are more likely to be taken up.

Research- Related:

There has been relatively little use for research thus far.

Quality Improvement:

Population-based estimates of disease risk, health status, and gaps in care are delivered to health care purchasers and to Group Health managers to direct resource allocation, care management programs, and quality improvement activities.

Future Plans:

Long-term plans are to improve integration of reports and data within EHR. No specific plans for expansion.

Group Health: Health Risk Assessment viewed in EpicCare

Document Text

Health Profile - Primary Care Team Report

Patient name:	FIFTY TEST	Gender:	Male
Date of Health Profile:	10/31/2013	Age at time of HRA:	38
Previous Health Profile:	10/31/2013		

Disease management concerns: Depression Care.
Other issues to consider: Body mass index (BMI), Nutrition, Risky Alcohol Use, Substance Abuse and Tobacco Use.

Care Currently Due — CLINICAL REFERENCES

- **o Pneumococcal Immunization**
- **o Tetanus Immunization**

Please note: Family history is not considered in breast cancer, colon cancer and cholesterol screening recommendations.

Future disease risk — CLINICAL REFERENCES

o Diabetes Risk	**Strong Risk**	
o Lung Cancer Risk	**Strong Risk**	

Please note: Family history is not considered in colorectal cancer, breast cancer, diabetes, and heart disease risk calculations.

Chronic Conditions — CLINICAL REFERENCES

- Depression	**Poor Control**	- PHQ8 score = 19 - No ongoing visits to a therapist for depression - Current medication for depression

Please note: If Depression Screening is not listed above, PHQ score was negative (low risk for depression).

Lifestyle Health Risk Factors — CLINICAL REFERENCES

- Alcohol use	**High Risk**	- Alcohol frequency: 2 or 3 times a week - Alcohol amount: 7 to 9 per day - Frequency of 6 or more drinks: daily or almost daily - AUDIT-C score: 10
	Readiness to change: Changed use of alcohol past 6 months	
- Nutrition	**High Risk**	
	Readiness to change: Plan to start making changes within 30 days	
- Substance abuse	**High Risk**	- Use of recreational drugs: yes
- Tobacco Use	**High Risk**	- More than 100 cigarettes ever smoked - No smokeless tobacco use in the last 7 days
	Readiness to change smoking: Plan to quit within the next 30 days	
- Weight and Height	**High Risk**	- Self-reported height: 5 feet, 8 inches - Self-reported weight: 265 lbs - BMI estimate: 40.4
	Readiness to change: I am already working on changing my weight	
- Physical Activity	**Moderate Risk**	- Walking (days per week): 0 days - Moderate (days per week): 0 days - Vigorous (days per week): 0 days - IPAQ Category 1
	Readiness to change: Plan to increase activity within 6 months	

Walk-through of the Patient Assessment Process

A new member is made aware of the HRA when s/he logs on to MyGroupHealth or alternatively, from a prompt from an employer that provides an incentive for completing it. If members do not complete it within 1 year, they receive a prompt. When the member completes the HRA (takes approximately 20 minutes) s/he is provided with immediate personalized health recommendations. A similar report goes immediately into EpicCare and is available for clinicians to review. Specific patient risk factors trigger recommendations based on Group Health clinical practice guidelines. Data are stored in Epic and in a database for analysis and aggregation.

Key themes

- Part of a comprehensive e-Health Risk Assessment
- There is 70% uptake of MyGroupHealth patient portal
- PRO data and other patient output from the HP are viewable as PDFs in the EHR
- Important enablers: Employer incentives to complete the e-HRA
- Barriers: Full integration with the EHR is costly and complex and not yet accomplished.

Sources: GHC internal documents; discussion (Paul Lozano, Rob Reid) (Reid 2010, Nelson 2012)

Cincinnati Children's Hospital Medical Center

Basic System Summary

The Cincinnati Children's system uses a tablet- and kiosk-based PRO data collection system that integrates via Welcome with the Epic EHR. Cincinnati Children's started collecting PROs for clinical use five years ago under a broad strategic initiative to improve patient outcomes with a focus on quality improvement methods and tracking of performance and outcomes metrics. Individual clinics were invited to identify 3 medical conditions on which to focus for their panel of patients. Efforts to collect PROs at the hospital level have ramped up over the past two years, with a focus on using the best possible methods and evidence possible with a trained psychometrician hired full-time to consult with clinics on measure selection and data analysis. Currently, a number of clinics are collecting a widely used PRO, the PedsQL™. The completion rate of patients eligible to receive the measure via tablet is 79%. Many of the disease-specific and functional measures developed and used at the clinic level are administered to targeted patient groups.

EHR Integration:

Patients are administered questionnaires at intake based on provider-specified variables pulled automatically from their EHR and date of previous survey (if previously administered).

Clinical Practice

PRO scores generated using an algorithm within Welcome are used at the point of care to inform the visit. In the rheumatology clinic physical function and pain interference are important patient outcomes that are tracked and reviewed at each visit. Changes in these scores are used to help identify and select the appropriate patient intervention (e.g., medication adjustment, physical therapy). In the Heart Institute, children with cardiomyopathy are provided a depression PRO. Depression has been found to impact clinical results in children with chronic diseases therefore the goal is prompt identification and intervention. The Food Allergy clinic is working to identify anxiety children experience from their allergic state. The goal is again prompt identification and intervention.

Research- Related

All administered measures must have a clinical rationale; nothing is collected purely for research purposes. Examples of research are: Evaluation of psychometric properties of a short version of the Children's Depression Inventory in a clinical setting, and for Type 1 Diabetes care.

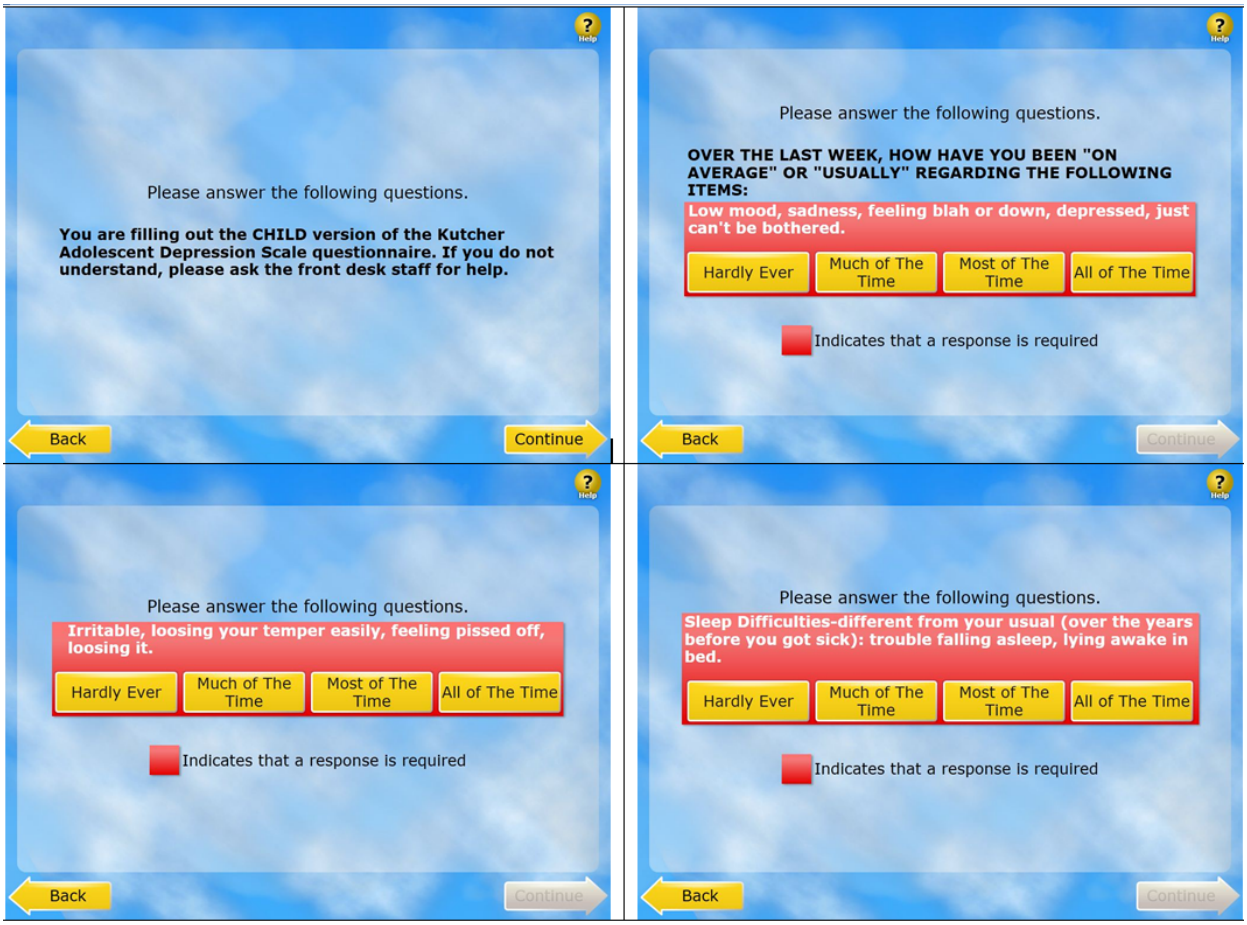
Quality Improvement

Key goals of quality improvement efforts are to reduce staff involvement in PRO administration and minimize patient burden. Many different quality improvement methods (e.g., swim-lane diagrams, process flow maps, PDSA cycles) have been applied at the clinic-level to streamline the integration of PROs into the clinic work flow and capitalize on electronic system automation to reduce staff burden. Results of these efforts include identifying patients that receive a large number of pre-visit PRO questionnaires (e.g., psychological batteries) and scheduling those patients to come in 20 minutes earlier.

Future Plans

Long-term goals are to create a clinical repository for CER, and integrate dynamic assessment (e.g., PROMIS CATs). Eventually, would also like to push all PRO and other patient information capture outside of the patient visit.

Cincinnati Children's: Child PRO assessment (Used with permission)



Walk-through of the Patient Assessment Process

At the registration desk, the patient is given a personal numeric code and either a portable electronic tablet or directed towards a computerized kiosk. The code is linked to their electronic medical record ID. A pre-programmed algorithm (based on diagnosis, age, time interval since previous assessment, and previous PRO scores) selects PRO questionnaires personalized for the patient. If PRO questionnaires are not completed in the waiting room, the tablet can be taken with the patient to the exam room. Clinicians review scores with patients during the clinic visit.

Key Themes

- Automatic PRO selection is driven by patient characteristics
- Strong institutional support and infrastructure
- Focus on automation and workflow integration using quality improvement methods

Sources: Discussion (Esi Morgan-DeWitt, Ian Kudel, Evi Alessandrini)

Kaiser Permanante Colorado (KPCO) Proactive Assessment of Total Health & Wellness to Add Active Years (PATHWAAY) for Seniors

Basic System Summary

The KPCO program is a comprehensive, population based method of screening to deliver evidence-based interventions for common geriatric issues, developed in 2011. PROs are seen as essential to handling geriatric problems. The goal was to develop a system of member health assessments including PRO that links to the EMR (Epic) and integrates with care to produce individualized action plans. Additional goals were to extract data from the EHR for quality measurement and research. Interactive voice response (IVR) was developed to allow data collection for patients not using KP.org (aka MyChart). IVR data are also integrated into the KP Health Connect (aka EpicCare) EHR. Pilot work was conducted in 2012 at 2 clinics, with implementation by July 2012 in all 24 KPCO primary care clinics. PROs collected are part of the Total Health Assessment questionnaire, including PHQ-2 and pain. Among seniors who rated the online process, 72% rated it "very easy" to use. This rating increased to 75% for the IVR process. Patients are given Personalized Prevention Plans (PPP) which are also integrated into Epic. People with positive triggers get direct telephone outreach. Use of automation and centralized support ($700K in salary+benefits) is estimated to save 3.2 FTE of added PCP time resulting in >$200K net savings.

EHR Integration: Both data collected via KP.org, and IVR data flow directly into KP Health Connect EHR. Actual data elements can be manipulated within Epic. Data are summarized in Health Trac, a PPP letter is created in Health Connect and is ready to be reviewed by the clinician. SmartSets are available to order subsequent testing and treatment. Data can then be extracted from the Epic Clarity database

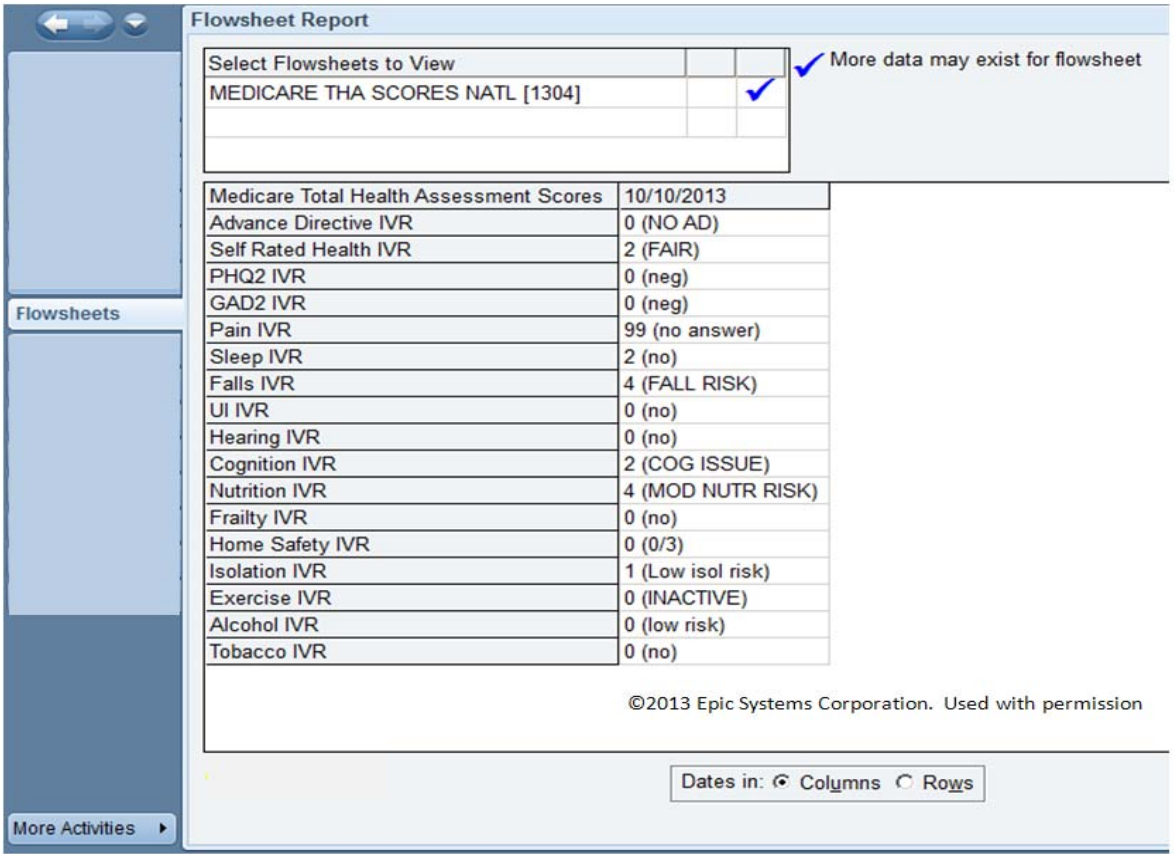
Clinical Practice Since July 2012 over 41,000 of a total population of ~90,000 seniors have completed an annual wellness visit, of whom 78% completed a THA, 72% of them before the primary care visit (40% via KP.org). Within Health Connect, screening is followed by evidence-based interventions for the related geriatric issues. For example, a positive screen for depression would be linked to a SmartSet for appropriate testing, treatment and referral. For the 65% of patients with at least one positive trigger, the team has contacted nearly half by phone for further assessments and to make algorithm driven recommendations and referrals.

Research-Related: Relatively little use for research thus far, but collaborating with the KP Institute for Health Research and others. There is a no-call list for patients who have opted out of research participation. A waiver of consent for research is applied to the remainder.

Quality Improvement: Metrics are developed as required by Medicare, including for depression and anxiety. There are links to other programs such as a depression care management team, and a CMMI funded COMPASS project using team care. No PRO related dashboards or pay-for-performance yet.

Future Plans: Expand to other KP regions including KPNorthwest, KPGeorgia, and KPSouthernCalifornia. Increase branching logic for PRO measures. Complete an inter-regional data repository. Increase capacity for use of tablet computers for in-clinic data collection. Develop history tool to be collected on a one-time basis at enrollment. Increase automation for generation and printing of Personalized Prevention Plans and data flow to reduce staff burden. Results of these efforts include identifying patients that receive a large number of pre-visit PRO questionnaires and scheduling them to come in 20 minutes earlier.

KPCO: Health Risk Assessment scores from Integrated Voice Response in EpicCare



Walk-through of the Patient Assessment Process

The process begins when a member calls for a non-urgent appointment or is scheduled for an annual wellness visit (AWV). If the patient is on KP.org the call center assistant assigns a THA to be completed 1-2 weeks before the visit; if not, it does warm transfer to IVR system. The data goes into the KP Health Connect EHR, and are summarized in Health Trac. Positive triggers go to Senior Assessment nurses who call patients to obtain more information. Medical assistants use data to complete a PPP which is put into Health Connect including instructions to print a copy for the provider. All information is available at the time of the patient visit ready to be used by provider. SmartSets make evidence-based recommendations and make documentation easier. If THA is *not* done before the visit, it is assigned to be completed the day after. Data are stored in Clarity and can be extracted for research and QI.

Key themes

- 50% of patients age > 65 are on KP.org
- Warm transfer at scheduling of Annual Wellness Visit assures that patients not on KP.org complete Total Health Assessment using IVR
- PRO data from THA collected both via KP.org and IVR are fully integrated into EHR
- Important enablers: CMS mandate to add a Total Health Assessment to the Medicare AWV; Central Program Office support with investment in IVR; building at regional level; cost effectiveness analysis
- Barriers: Limited functionality of EHR, lack of universal internet connectivity in facilities

Sources: KP internal documents; discussion (Matt Stiefel, Wendolyn Gozansky, Eric Mayer)

Minnesota Community Measurement (MNCM) – Essentia Health System

Basic System Summary

The MNCM system is free-standing statewide data collection effort that includes PRO measures. MNCM is a non-profit organization that emerged in 2002 out of a community-wide need for a consistent way of measuring and reporting health care quality measures to the community. Minnesota's health plans were already working together to sponsor the Institute for Clinical Systems Improvement (ICSI) for quality improvement. The medical directors of these health plans wanted a single, combined report to compare patient care and outcomes statewide, including public reporting. An explicit goal is to support the CMS triple aim of improving Health, Experience, and Cost. Their first performance report was on diabetes care; by 2004 results were published on the public website MNHealthscores.org. Capturing patient experience of care has included the PHQ-9, the Asthma Control Test (ACT), Asthma Therapy Assessment Questionnaire (ATAQ), Asthma Control Questionnaire (ACQ), functional status tools for Knee Replacement and Spine Surgery.

EHR Integration:

Data are collected electronically at each site, but are not necessarily integrated into local EHRs. At Essentia Health, a health plan that includes 18 hospitals and 68 clinics and that utilizes MNCM, data are increasingly collected via the Epic "MyHealth" patient portal (25% enrolled). The remainder are collected during patient visits, or mailed paper questionnaire, or phoned to complete data collection. Quality metrics are built in to their Epic EHR. Data are exported to an external Quality Data Warehouse.

Clinical Practice

MNCM works with many clinics, hospitals, and medical groups in Minnesota, Wisconsin, and North and South Dakota. At Essentia, depression screening using PHQ-9 is linked to a Depression Clinical Workflow Guide provided by ICSI, and a Help and Healing online toolkit that gives providers evidence-based treatment guidance and easy-to-use resources to assist in depression recovery. Some of the Essentia clinics have specially-trained RN care managers to work one-on-one with patients who have depression.

Research-Related:

MNCM is a grantee of the Robert Wood Johnson Foundation Aligning Forces for Quality (AF4Q) program.

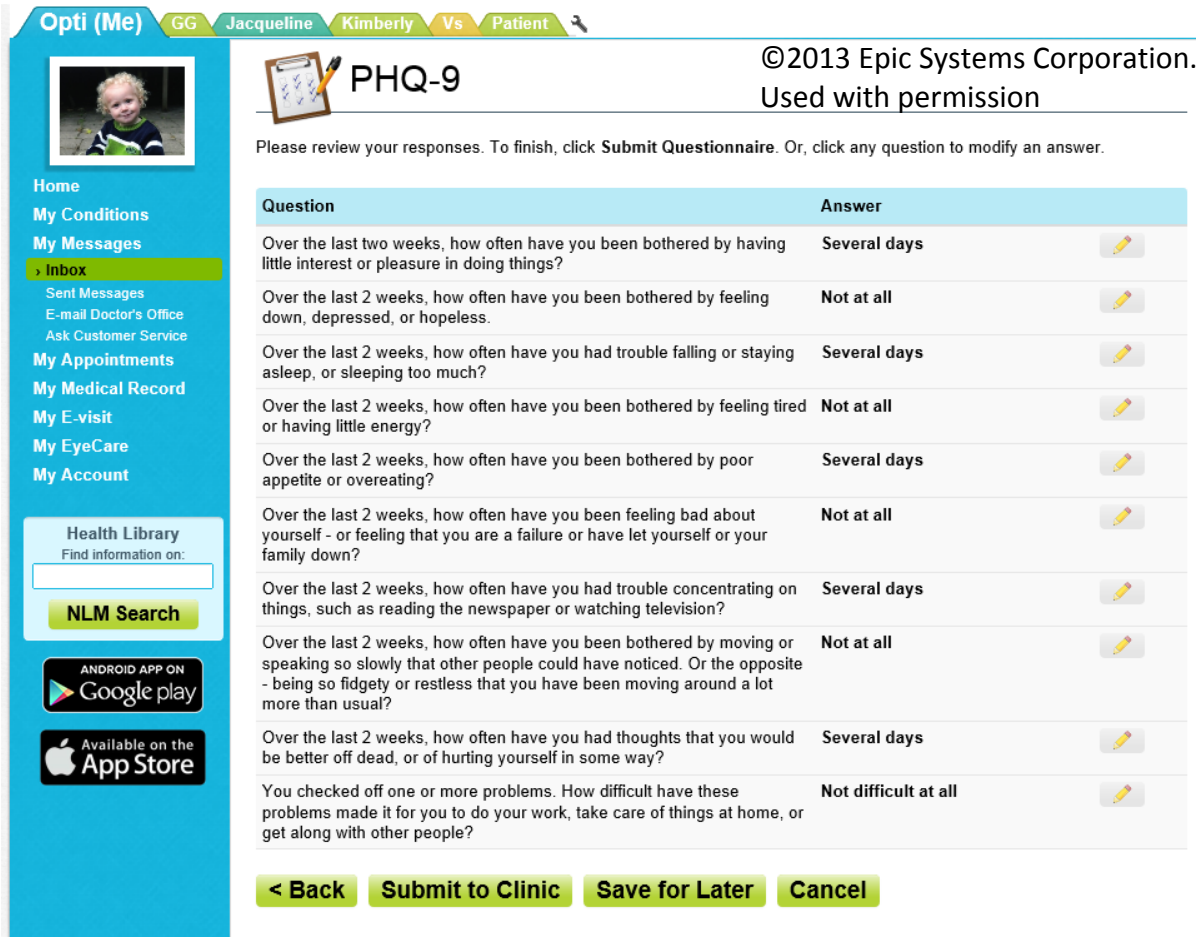
Quality Improvement:

The PHQ-9 based performance measure has been endorsed by NQF. Currently, MNCM reports on over 76 measures at over 315 medical groups and 672 sites of care. Reporting of PRO measures is linked to statewide quality improvement programs such as DIAMOND (Depression Improvement Across Minnesota). At Essentia Health, quality metrics are built into the EPIC EHR and are used by the performance improvement team.

Future Plans:

Long-term goals are to expand to include both cost and experience of care, and Additional PRO measures for spine surgery, total knee replacement, and others.

Essentia Health: After answering questions, patient can review and edit answers



Walk-through of the Patient Assessment Process

At Essentia Health, all patients with a recent visit diagnosis of depression complete the PHQ-9 at a minimum of every 6 months. A total of 25% of Essentia patients are enrolled on the Epic "My Health" patient portal. For patients with depression, if the patient does not complete the PRO online, an aide calls or mails them to obtain the data. PHQ-9 data are integrated into EpicCare EHR with standardized workflow for evaluation and treatment. Quality metrics are calculated and addressed by the local quality improvement team and are also reported to the State report card.

Key themes

- Measurement of PROs supported by pay-for-performance at most health plans
- Reporting is made mandatory by Minnesota Department of Health
- Data collected at clinics and health plans; results are fed back and made publicly available

Sources: Website, discussion (Tina Frontera MNCM COO; Patrick A. Twomey, MD CMO Essentia); http://mncm.org/ ; http://MNhealthscores.org/; http://mncm.org/submitting-data/provider-tools/

University of Pittsburgh Medical Center

Basic System Summary:
The UPMC system is a PRO data collection system built upon the Epic EHR. In 2004, this group implemented a standardized electronic intake system in an academic general internal medicine practice for collecting PROs and other patient data (exercise, smoking status, review of systems). The results from this 10-year effort have laid the foundation for a health system-wide initiative to integrate PROs into the health care system. In the next 5 years, electronic clinical intake, including PRO and patient history collection, will be integrated into UPMCs EHR across 861 outpatient practices in 35 counties.

EHR Integration:
PRO data collection is integrated into Epic, through MyChart and Welcome. Patient questionnaires are seen by the clinician within the visit navigator, allowing item level and total scores to be displayed to the clinician, and are available in a flow sheet for review outside of the clinical encounter.

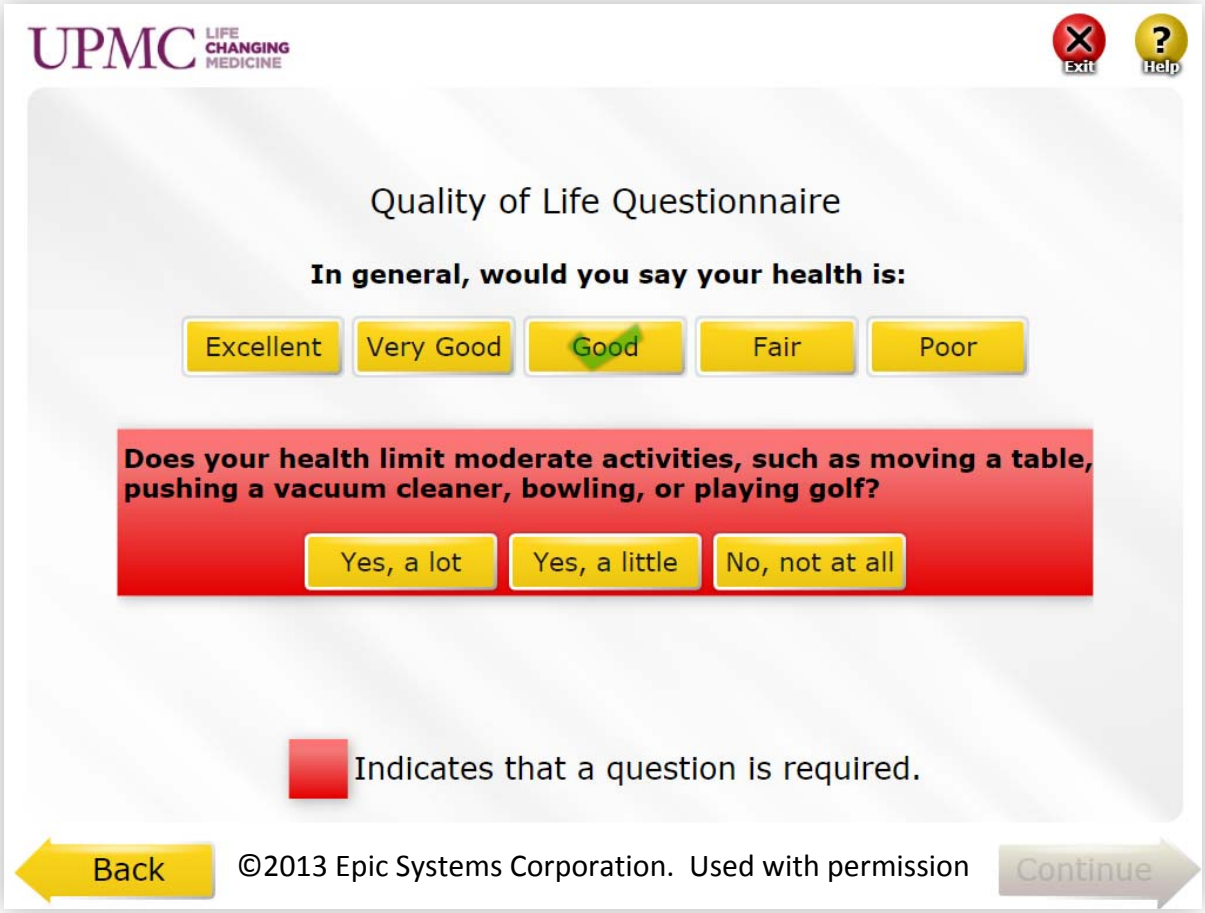
Clinical Practice:
The system is designed primarily for clinical practice use. Standards to measure an individual construct are set at the system level. For example, most clinics use the same general quality of life measure (SF 12 or SF 36), while disease-specific questionnaires are more variable (e.g., Seattle Angina Questionnaire, Pain Disability Index, Oswestry low back pain questionnaire). In settings with a compelling alternative measure (e.g., the FACT for cancer), those alternative measures are used. Many different longitudinal reporting options are available with intervention overlays. For example, clinicians can graphically overlay interventions or medication changes on PROs to help understand the impact of intervention on patient-centered outcomes. Unanticipated benefits include the planned use by the physical medicine and rehab group to provide additional objective evidence of treatment benefit to argue for coverage of some clinical care delivered. In addition to individual-level patient data, the “real-world” group level data can be used to advocate for more global policy changes.

Research-Related
While the focus of this work is clinical care, as with all data collected for clinical use, it is available for research and quality improvement purposes as well. These data can be reported out with the same ease as other electronic data for use by investigators.

Quality Improvement
System specific: Every week managers of each group are sent usage statistics: number of patients, percent of questionnaires completed and the change in percent completion from the prior weeks. Departmental and practice managers can compare completion rates across practice form the same service line. If a clinic reports consistent completion rate under 80%, operation teams are sent in to review and identify the problems and work with the practice manager to overcome these issues.

Future Plans
The program goal is to help meet meaningful use requirements (including communication between the provider and patient outside of the care setting), decrease costs, provide opportunities for new models of care, and leverage in new research opportunities.

UPMC: PRO item in Epic Welcome for patient completion



Walk-through of the Patient Assessment Process

All patients scheduled for a visit automatically receive a questionnaire within a time window deemed clinically appropriate according to the patient and the type of visit (e.g., 1 week for physical medicine and rehabilitation, 2 weeks for cardiology visits). Patients can fill out the questionnaire at home or in the clinic. Our goal for completion time is under 10 minutes. Questionnaires vary based on the clinic type. Clinicians are required to document in the EHR when they have reviewed the patient history information, PRO questionnaires are filed automatically.

Key themes

- Scaling-up successfully to health system-wide integration
- Focus on the patient-provider experience
- Strong institutional support

Sources: Interview and email communication (Rachel Hess)

Duke University Patient Care Monitor

Basic System Summary:
Patient Care Monitor (PCM) is an electronic system to collect and store PRO measures and provide the scores to cancer care providers. The vision for PCM was to fill the critical need for continuously aggregating information at the point of care with reliable, high quality, and clinically useful data. The foundation principle was around the question of "how do we wire up healthcare to include the patient voice" and how PROs can capture the patient voice in a systematic and clinically relevant way.

EHR Integration:
Integration of the PCM was accomplished at the site level. At Duke programming was used to integrate PCM with the data warehouse and patient scheduling information.

Clinical Practice:
Summary reports are generated that can be viewed by the entire medical team, clinic providers (nurse, social worker, PA/NP, physician), and staff. The reports are color coded and designed to show doctors a pattern quickly. PRO scores can trigger immediate patient education actions or flag patient eligibility for symptom-specific interventions (e.g., depression, sexual function, sleep disturbance). On the provider side, results are included in the routing sheet.

Research-Related:
Data can be collected at point of care for research purposes. Consent forms are appended as necessary and tailored to patients who are targeted for study enrollment. Otherwise, PRO data are available from the data warehouse for retrospective studies.

Quality Improvement:
PRO data has been integrated into many quality improvement initiatives. For example, using PRO pain scores, they have been able to predict how many pain physicians are necessary to address patient pain concerns.

Future Plans:
Duke plans to roll out PCM to multiple sites across the country.

Duke Patient Care Monitor: Physician screen showing embedded scores to aid interpretation

	15. Psychiatric				
↑	Crying/feeling like crying	6	·	·	3
	Nervous, tense, anxious	6	·	·	8
	Worry	6	·	·	8
	Feeling hopeless	5	·	·	4
	Sad (depressed)	5	·	·	6
	Feeling helpless	5	·	·	6
	Lost interest in people	4	·	·	6
	I would be better off dead	2	·	·	2
↓	Absence of pleasure	2	·	·	5
↓	Feeling worthless	2	·	·	5
	Feeling guilty	0	·	·	2
	16. T-Scores				
◑	Distress	67.1	·	·	68.7
	Despair/Depression	65.1	·	·	68.5
	17. Physical Functioning				
	Hard work or activity	**9**	·	·	**9**
	Attend paid job	**9**	·	·	**10**
	Household work	**7**	·	·	**5**
	Run errands	**7**	·	·	**5**
	Run	**7**	·	·	**8**
	Function normally	6	·	·	5
	Light work or activity	6	·	·	7
	Walk	5	·	·	4
	Attend social activities	5	·	·	5
	Bathe or dress	4	·	·	2
	Driving	4	·	·	5
	Cook for self	4	·	·	5

Walk-through of the Patient Assessment Process:

The walk through is site-specific and variable. For instance, patients in one clinical oncology clinic are given a handheld tablet computer at check-in to complete a comprehensive, validated PRO questionnaire measuring physical symptoms, impaired performance, impaired ambulation, treatment side effects, distress and despair. PRO scores are summarized for the clinician's review using a color-coded report that includes current scores and change over time. Other clinical sites may use desktops, kiosks, or mobile devices to have patients complete PROs prior to coming in for the visit. Providers need to acknowledge to patients that they have reviewed the PRO data. This is key to get patients to report prior to their next visit and, in turn, to have high quality and reliable data. There is also a patient-version of the report that providers more detailed explanation than the care team's version.

Key Themes:

- Built based on rapid learning health care infrastructure
- Includes system review and visual aids
- Facilitates patient education and enrollment into symptom management interventions when they meet enrollment criteria

Source: Interview (Amy Abernethy); Abernethy 2009; 2010 a,b

University of California Los Angeles/University of Michigan My GI-Health

Basic System Summary:
The My GI Health Project (myGIhealth.org) is a web-based PRO collection and reporting system developed by the University of California, Los Angeles and the University of Michigan (Center for Health Communications Research) for use in GI clinics. Currently this system is used in three clinics (UCLA, West Los Angeles VA, and U Michigan GI clinics). This system was designed to collect PROs and provide interpretation for clinical use. The focus is generating GI-symptom scores (e.g., reflux, gas/bloating, abdominal pain, constipation) and building a standardized patient history of presenting illness (HPI) that incorporates PRO information. It also provides patient education with recommendations tailored to their PRO scores. My GI Health uses the PROMIS GI Symptom Scales, enabling score comparisons to the general U.S. population.

EHR Integration:
This system is designed to work with EHR systems, but all integration is done manually by the provider. PRO-based patient histories and scores can be added into the EHR through copy and paste function commands. While a separate system, My GI Health has created features to create the impression of integration between their tool and the EHR systems in use at each site. Two methods have been used: (1) allow easy access to the My GI Health system by placing a launch button in the EHR tool bar. (2) Providers use the same log-in credentials for the My GI Health system as their EHR. Two data servers are used for this system. Patient questionnaires are completed and scored through UCLA. All educational content that forms the "personal educational prescription" occurs through a server at the University of Michigan.

Clinical Practice:
This system was designed specifically to supplement clinical practice. Providers can customize the experience for both themselves and their patients using various settings. These options range from restricting when patients can review information to how much information they view to restricting types of patients who enter the system. Providers can also select what information is reported to them. For example, they can select the cut points for symptom severity. Patients receive a personalized educational prescription based on their scores that incorporates patient-centered animations, selected websites, and other online resources based on their PROMIS "fingerprint" of scores.

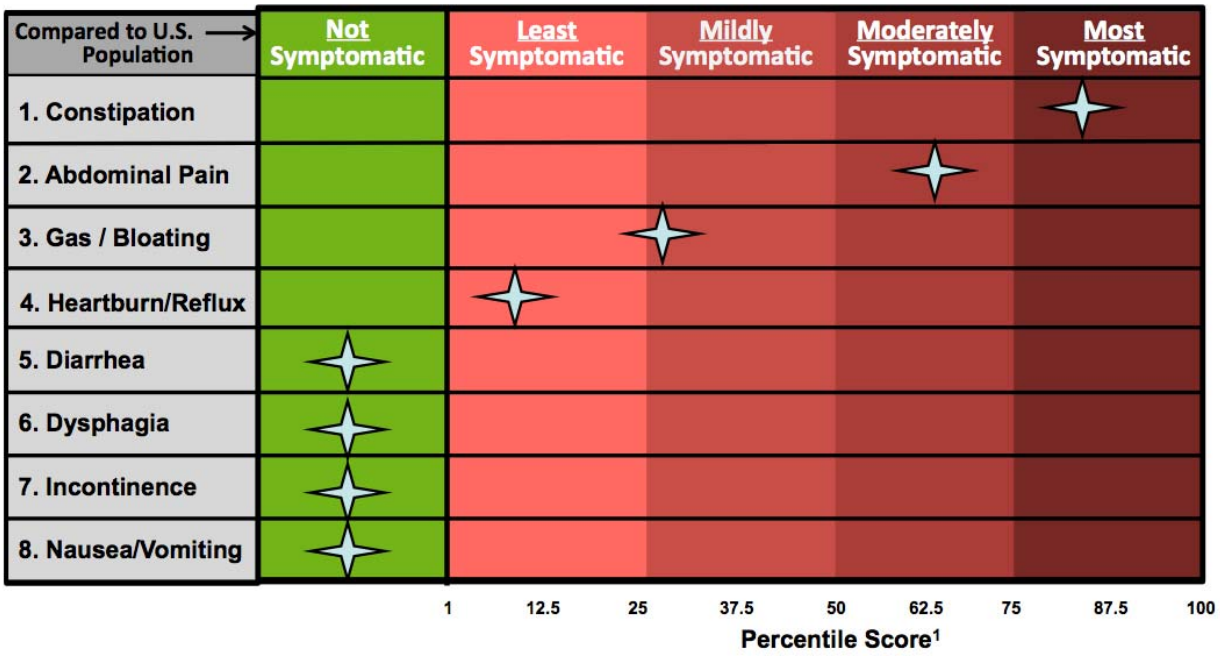
Research-Related:
Future plans include a "big data perspective" and patient-reported informatics including incorporating wireless biosensors to the collection of PRO scores. The system is currently funded through a PROMIS supplemental grant to be tested in a randomized controlled trial that will begin in Winter 2013 and end in Spring 2014. Another study is currently testing the quality of the physician-generated HPI notes vs. the My GI Health-generated automated HPI notes.

Quality Improvement:
None

Future Plans:
My GI Health is expanding in a number of ways: (1) Developing an iPhone "native app" for patients to report their symptom information. (2) Considering the administration of assessments beyond the clinical setting into the community to promote patient education and self-management. (3) In discussions Athena health, to pilot an EHR-linkage.

UCLA/University of Michigan: My GI-Health Report (Used with permission)

Interpretation: Your answered questions about each of 8 GI symptoms. The answers were scored and then combined to form 8 GI symptom scales, represented as percentile scores (ranging from 1–100) based on the U.S. general population (higher=worse). This "heat map" shows your symptom scores reported within severity quartiles (red bars). The symptoms are presented from most to least severe, based on comparison with the U.S. population.



[1] Each composite score is expressed as a percentile rank compared to people in the U.S. population reporting the same symptom. The scores are presented within severity quartiles (red bars).

Walk-through of the Patient Assessment Process

All patients receive a letter prior to their visit with information about the system and how to log on via the web. Patients can then register for the system and create log-in credentials. They see a welcome video (that can be personalized by each provider), complete a symptom assessment and provide a history of their symptoms. Once scored, patients may be linked directly to educational resources and scores. When patients can view scores and access educational content is based on provider settings. Providers may choose to wait to release these features after the patient visit. Patients and providers then review and discuss the symptom report at the upcoming visit.

Key themes

- Built around a body system (GI) and related symptoms, not disease-specific
- Providers are given a high degree of individual control on how and when PRO information is reported to them and their patients
- Considerable preliminary qualitative work with physicians was conducted to develop and finalize symptom reports

Sources: Discussion (Brennan Spiegel)

University of Washington-Center for AIDS Research Networks of Clinical Systems (CNICS)

Basic System Summary

The UW System is a web-based, self-administered patient-reported assessment tool integrated into routine primary care for adult HIV-infected patients. The goal of this system is to collect clinically-relevant patient-reported data and integrate it into clinical care. It was first implemented as a research study modifying a PRO platform used in oncology settings for HIV care and research. The ability to tailor to specific clinical sites was one of the keys to succeeding in various settings. The developers worked with patients, and providers to identify which patient domains were actionable, could inform clinical care and research, and were relevant to the HIV/AIDS population. PROs integrated into the system includes depression, medication adherence, and drug and alcohol use. Preliminary findings were used to develop institutional buy-in and support, and have allowed for further development and integration with broader quality improvement efforts. PRO data collected by this system are integrated into a national disease specific research network.

EHR Integration:

Integration into the EHR is site-specific and variable. In some sites the system works side-by-side with the EHR, enabling data elements to be pulled from the EHR system and put back into the EHR. All assessments are done through a separate system. The benefit of this type of integration is that it has allowed easier implementation at other sites (e.g., University of Alabama) with different EHR systems. Functionality and content is "adjusted" according to site requirements for data to flow between the two systems. One of the biggest challenges has been navigating the variety of EHRs across sites and cross-platform adaptation of functionality.

Clinical Practice:

The system is currently used in clinical practice with s cores directing clinical decisions. For example a positive response to the suicidal ideation item is flagged, and the mental health team is notified immediately so that the patient is seen by a mental health worker before the provider. An evaluation showed that using this system has lead to an increase in depression screening, identification of medication adherence, and previously-undocumented substance use.

Research-Related:

This assessment has been implemented into HIV clinics as part of the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) cohort. PRO assessments have been completed over 29,000 times.

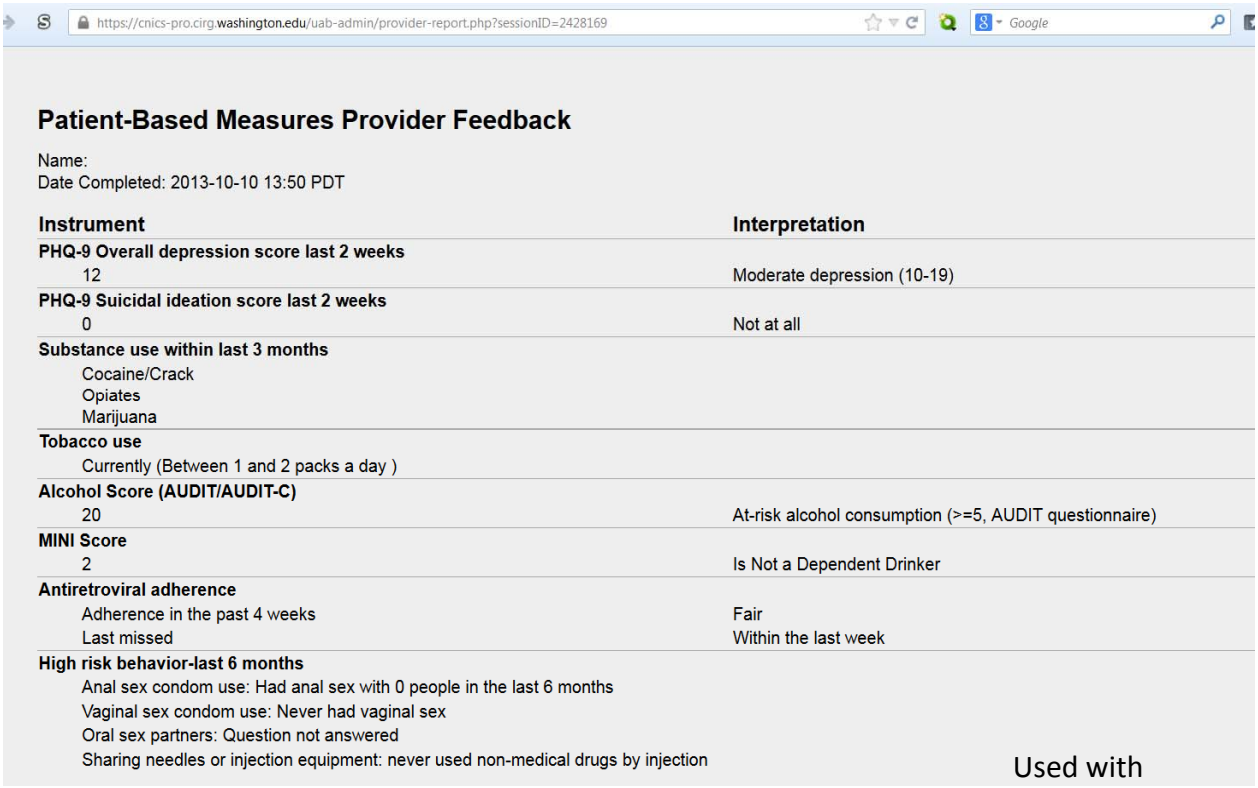
Quality Improvement:

The UW clinic has implemented Plan-Do-Study-Act cycles to identify and address PRO issues surrounding clinic flow, and how to integrate the scheduling and delivery of assessment results.

Future Plans:

They are currently expanding the clinical assessment to a number of clinics within the Community Health Applied Research Network (Likumahuwa 2013). Grants have been submitted to examine how this information can be tailored for patients.

University of Washington: Feedback to providers on patient PRO scores



https://cnics-pro.cirg.washington.edu/uab-admin/provider-report.php?sessionID=2428169

Patient-Based Measures Provider Feedback

Name:
Date Completed: 2013-10-10 13:50 PDT

Instrument	Interpretation
PHQ-9 Overall depression score last 2 weeks	
12	Moderate depression (10-19)
PHQ-9 Suicidal ideation score last 2 weeks	
0	Not at all
Substance use within last 3 months	
Cocaine/Crack	
Opiates	
Marijuana	
Tobacco use	
Currently (Between 1 and 2 packs a day)	
Alcohol Score (AUDIT/AUDIT-C)	
20	At-risk alcohol consumption (>=5, AUDIT questionnaire)
MINI Score	
2	Is Not a Dependent Drinker
Antiretroviral adherence	
Adherence in the past 4 weeks	Fair
Last missed	Within the last week
High risk behavior-last 6 months	
Anal sex condom use: Had anal sex with 0 people in the last 6 months	
Vaginal sex condom use: Never had vaginal sex	
Oral sex partners: Question not answered	
Sharing needles or injection equipment: never used non-medical drugs by injection	

Used with permission

Walk-through of the Patient Assessment Process

Patients are scheduled to fill out a PRO survey 20 minutes prior to their provider visit using a touchscreen tablet in the clinic. Patients fill out surveys every 4 to 6 months. Results are delivered to providers and case managers at the time of the patient visit. Many aspects of this process are tailored to each clinic.

Key themes

- Integration into a large, national research network that integrates clinical and PRO data
- Developed quality improvement efforts around PRO collection to generate institutional buy-in
- Focused on elements of care that has a desirability bias in face-to-face interactions: medication adherence, depression screening, drug use
- Expanded beyond PROs to other patient-reported data (PRD)
- Impressive expansion efforts into HIV clinics and community health centers

Sources: Interview and email communication (Heidi Crane); Crane 2011; Fredrickson 2012; Tufano 2010

SYNTHESIZING ACROSS THE CASE STUDIES

The systems profiled here represent a broad range of functionality, patient populations, and applications involved in PRO collection and EHR integration. A synthesis of the case studies aims to provide insight into the key components and considerations associated with this intervention. Below, we summarize the systems' features, outline the key considerations related to the systems' development and deployment, discuss the themes that emerged from this review and identify barriers to and facilitators of PRO integration in the EHR.

Summary of Systems

The case studies above cover a range of PRO applications, including health plans, clinical efforts, and research applications. PRO collection efforts by three health care plans — Kaiser Permanente Colorado (KPCO), Group Health, and Essentia Health — illustrate a variety of applications of PRO collection at the plan level, including clinical care, population-based screening, and quality-of-care evaluation efforts. Hospital-wide PRO efforts at Cleveland Clinic and Cincinnati Children's represent examples of the use of PROs in specialty care and the expansion of PRO use in a hospital setting. Examples of clinic-based, disease-specific PRO collection include UCLA/Michigan's My GI Health program (GI clinics), the University of Washington/CNICS (HIV), the Dartmouth Spine Center (spine), the Patient Care Monitor at Duke University (cancer), and the University of Pittsburgh Medical Center (primary care). Lastly, we have included Epic MyChart, a patient portal that includes a PRO collection module, and that is an element in many of the other systems described above. MyChart is similar with respect to the assessments and design of the external collection tools described in this review.

Clinical care efforts primarily focus on providing information for a physician to use during the patient visit, but some systems also include features that elicit information for follow-up evaluation (e.g., Smart Set at KPCO, and Care Paths at Cleveland Clinic). Quality improvement efforts were most commonly aimed at evaluating PRO collection, but Essentia reports their PRO scores as part of a statewide (Minnesota) quality improvement effort, including public reporting. Research efforts are generally limited but are part of future expansion plans. A few sites (UCLA/Michigan, Cleveland Clinic, Cincinnati Children's, Duke) have integrated these systems into methodological and

clinical research. UW/CNICS have made integrated PRO and clinical (EHR) data available to a nationwide HIV research network. And Cleveland Clinic includes data from its PRO systems in its ongoing reports on cost-effectiveness research in multiple disease areas.

Considerations of the Cases by System Features

This section presents a general summary of the system features across the different systems profiled, supplementing the content included in the case studies. Topics covered include (1) System Design/Implementation, (2) Measure Selection, (3) Administration/Data Collection, (4) Reporting and Interpretation and (5) Analysis.

(1) System Design and Implementation

Concept and Purpose. For most of the systems examined, PRO data collection and integration were intended to meet a specific clinically-oriented need by incorporating the patient perspective into care. The origins of each system vary considerably; each confronted different barriers and enabling factors in accomplishing PRO data collection and integration. Some systems were developed based on other research-related electronic data collection efforts, such as patient registries (UCLA) and clinical research studies (UW). Others were developed explicitly for use in clinical practice (UPMC, Duke). A third type of system design, most commonly at the health plan level, focused on screening patients to target interventions (KPCO), engage patients (Group Health) or monitor quality of care (MN). One barrier to integration identified was a lack of knowledge by some developers about precisely how their system is designed to capture, store and report PRO data, as well as the points at which it is integrated into the EHR. This suggests a knowledge gap with respect to system design.

Expansion. While all of the systems described here implement PRO data collection in multiple settings (clinics or hospital-based practice sites), some started small (e.g., a single clinic) and expanded over time. These systems often identified clinical "champions" – early adopters already knowledgeable and interested in implementing electronic PRO assessment in their clinic. Systems with wide-spread adoption reported the development of best-practices and utilized multidisciplinary design teams to streamline implementation. These teams evaluate current workflow, design the PRO

collection to conform to current clinic workflow and generate recommendations that can range from PRO content to specific hardware needs. An unexpected, yet common, barrier was implementation issues due to limited wireless internet access in a clinical location. Most of the data collection systems collect PROs through a web-based platform. Limited or intermittent connectivity presents a barrier to collecting and storing the PRO data before linking them with the EHR.

(2) Measure Selection

Content. Although measure selection varies by system, all organizations focus on collecting clinically-relevant PRO information. The range of content and measures available was handled differently by each system. Some organizations allow clinicians to select virtually any measure or individual question they want to include, others establish a limited set of measures to be used across sites. Between these two options, some systems present a compromise by letting providers select among a limited number of “approved measures” within specific domains, or by allowing specific add-ons to a core measure set. These different approaches to content selection provide different trade-offs with respect to provider engagement, the ability to standardize measures across clinics/sites, and the depth and specificity of PRO information available to clinicians.

Modification & Implementation. Some systems focused on removing redundancy and limiting PRO questionnaire length using skip patterns, screening based on disease characteristics and automating measure selection based on patient characteristics. One issue identified by several systems was the difficulty encountered in adapting legacy, paper-based PRO measures for electronic use. Limitations in the visual design of systems present barriers to maintaining fidelity when adapting PRO measures to an electronic format. It was uncommon for electronic surveys to be skeuomorphic (to resemble the paper forms). Another barrier was the limited evidence for the reliability and validity of these new formats to ensure that they yield useful data for research.

Design Considerations. The selection of measures and how they are modified and administered require decisions that may limit the usefulness of information for both research and practice applications. For example, a clinically-focused single item

measure may not provide sufficient measurement reliability to serve as an appropriate outcome variable for a research study. Conversely, a lengthy, research-focused multi-item scale may not be feasible for clinical use.

(3) Administration/Data Collection

EHR Integration. Two types of EHR integration were identified: (1) systems that fully integrate PRO data into an EHR system (including collection within the EHR, such as MyChart) and (2) systems that collect, store, and report PRO data independently, with only the final scores integrated into the EHR. While fully integrating PRO data in the EHR has definite advantages, benefits of the latter approach are that it allows PRO collection across different EHR system software. However, this may limit integration to a small number of data elements that can be easily integrated (e.g., summary PRO scores), thus limiting functionality in the EHR itself.

De-linking PRO Assessment from the Patient Visit. Most of the case studies that use PRO data in the clinical encounter allowed patents to fill out surveys online prior to a visit, or at set intervals after the visit at a time most useful for evaluating recovery. However, patient participation rates for long-term monitoring are currently low, ranging between 20-30%. Some systems were more optimistic than others about how much that number will increase as web-based collection becomes further integrated into care. Greater integration of assessment opportunities outside of the patient visit offers significant benefits to clinic workflow by reducing time spent during a clinical encounter. Health plans with active patient portal systems suggested that patients, even those who are older and may have more limited online experience, can complete assessments prior to visits. For example, Group Health's Health Risk Assessment has shown high portal-based completion rates prior to an annual visit. KPCO seamlessly integrates interactive voice response (IVR) and electronic capture, allowing for impressive coverage of 78% (40% via the patient portal) for pre-visit screening of elderly patients.

(4) Reporting and Interpretation

Audience. The audience for PRO information varied across different systems and applications, including the patients themselves, clinicians, health care managers, insurers and the public. Patient-level scores and change in scores are presented

primarily to the provider, whereas aggregated reporting is used for clinic-level evaluation and quality improvement efforts.

Format Variations. The format, content, and mode of data collection (paper, electronic, vs. both) and display can differ both between and within sites. For example, Dartmouth employs multiple modes of administration to maximize completion rates. One repeated theme was the current reporting limitations of PRO data displays (especially patient displays) within the EHR. Even the data collected directly within an EHR may be stored as an image file rather than discrete data within the record, which limits both provider access and availability for secondary use.

Automation. The PRO assessment results may trigger a wide range of actions. The most common alert identified in this review was the identification of a positive indicator for suicidal ideation. When this occurs, clinicians are notified immediately. Other examples of automation include the "SmartSet" developed at KPCO whereby a positive depression screen triggers a series of evidence-based orders for testing, treatment, and referral. PRO scores can also be used to tailor personalized educational interventions. However, this type of integration was only identified in specialized care settings where disease-specific PRO information could be used to direct patients to appropriate advice or other information (e.g., GI symptom self-management). At UPMC, PRO measures are being used by rehabilitation clinicians to provide information that argues against payment denial for aspects of the clinical care that they deliver.

(5) Analysis

Clinical Value & Efficiency. Analyses conducted at several of the sites highlighted in this review aimed to generate evidence of high-quality care (indicators of patient management) and the benefits of PRO use in the clinical encounter. This includes measures of patient and provider satisfaction (Cleveland Clinic), improved clinician notes (My GI-Health), and patient self-reported medication adherence (UW). Quality improvement efforts tended to center around improving the integration of PROs into the workflow. In one case (KPCO), cost savings were calculated, illustrating some of the benefits of PRO integration and automation.

Major Themes

From the article review, qualitative interviews, and case-study synthesis, four major themes emerge regarding the use of PROs in the EHR. These themes are (1) System Customization, (2) Balancing Research and Practice Goals, (3) Demonstrating Value, and (4) EHR Integration and Limitations.

Theme 1: System Customization

Clinical practice encompasses a broad range of settings, conditions, and patient populations. Therefore, it is difficult to develop a single standard EHR that fits all health care environments. Studies have shown that when non-customized, "off-the-shelf" EHR systems have been adopted, the result has been problems with communication, missing records, and decreased productivity (Maekawa 2006). A major theme that was identified in the case studies was the need to customize systems to the settings in which they were being used. We found that a great deal of customization appeared to be necessary across all systems. Of particular importance is customizing the basic software so that it is tailored to the workflows of the specific institution.

For maximum interoperability, an ideal EHR system would have a standardized underlying record, plus interfaces that can be customized to each specific environment. Having a standardized underlying record increases the ability to abstract and combine data across systems whereas customization enables PRO collection to fit within the clinical workflow, thereby facilitating clinician, staff, and patient buy-in. However, the number of changes necessary even for "off the shelf" products suggests that implementing PRO collection requires a high degree of expertise to be successful and sustainable.

There is limited guidance and few examples to inform the implementation of electronic PRO collection. The degree to which a system is customized has implications for the accuracy and comparability of information when used for broader clinical, quality, or research goals. Whether electronic PRO collection represents the expansion of a current successful effort, a new user of an existing PRO collection system (e.g., Epic), or a new PRO system developed *de novo*, systems need to consider the opportunity for large scale PRO-EHR integration. Currently there is limited information on how

differences across systems can impact the quality and type of data reported. However, it is likely that large differences, within or between systems, create barriers to scaling up collection, producing PRO data reports and integrating PRO data for large-scale evaluations.

There are other potential disadvantages to customization. There are up-front costs needed to customize a standard system to a specific implementation. Health care providers and the implementation team must invest a significant amount of time if customization is to be responsive to local workflows and needs. Costs increase if additional interfaces are needed.

Theme 2: Balancing Research and Practice Goals

Electronic PRO assessment facilitates opportunities to use data collected for a single purpose in multiple different ways. While there were variations among systems in the focus on research versus practice, all of the systems that we reviewed have considered how collected PRO data can be extracted for secondary use for research, practice, and quality improvement.

For nearly all of the systems described in the case studies, real-time use in clinical practice was the guiding force to integrate PRO data into their EHR systems. (The exceptions were Group Health, for which the delivery of personalized health-promoting recommendations to ambulatory patients was of equal importance, and Minnesota Community Measurement, for which quality measurement and quality improvement were also central goals). For some of these systems, there is limited use of PRO information for research efforts. One system (UPMC) explicitly stated that they did not collect any un-actionable data, preferentially retaining only PRO measures that have direct clinical relevance. A few systems focused on broad quality of care evaluation efforts. MN Community Measurement and Essentia are one such example, in which PRO scores were used to measure and report quality of depression care and guide pay-for-performance. Additionally, a minority of systems, with UW/CNICS being one example, indicated the use of PRO data in broader, population-based research efforts. Balancing goals for research and practice requires numerous considerations all within the limited timeframe of a clinical visit. Considerations include system design, patient

burden, staff buy-in and data standardization, all within the limited timeframe of a clinical visit. Each of these areas requires attention for expansion to broader research use beyond the clinical setting. Systems where population health was a high priority, such as KPCO and Group Health, emphasized data collection prior to clinical visits. Both rely on strong patient participation in their patient portals.

Theme 3: Demonstrating Value

Most systems identified stakeholder buy-in as both a barrier and a facilitator of PRO use and integration. Key stakeholders identified in these interviews and the literature were patients, clinicians and other staff and institutions (including employers and payers, depending on the system). Ultimately, patient participation drives the collection of PRO information and ability to use it in care. Methods for increasing patient involvement include allowing patients access to their scores and what they mean (My GI Health, Group Health) and linking to tailored patient education and interventions driven by PRO scores (My GI Health, PCM, Group Health, KPCO). Including patients at every point from questionnaire completion to reviewing results can provide a compelling opportunity for patient engagement. However, systems collecting PROs within the EHR were generally unable to generate patient-focused content and interpretation, instead relying on clinicians to present and interpret PRO information for their patients.

Clinician engagement drives the incorporation by practitioners of PRO information into patient visits. For systems that are free-standing and link into EHRs (e.g., My GI Health), use of PRO information requires clinicians to take extra steps to access a separate, non-integrated system. As this requires effort beyond accessing a patient's EHR, additional motivation is necessary. Systems take a number of different approaches to facilitate clinician buy-in, from preliminary measure selection (Cincinnati Children's), a streamlined focus on clinically-relevant content (UPMC), and allowing clinicians to control the reporting features (e.g., alerts) of the system (My GI-Health). Each strategy is targeted to engage the clinician in this process. Several of the organizations (e.g., Dartmouth, UPMC) secured the initial involvement of clinical champions in each program area. These early adopters were involved in many different aspects of system implementation, including: identifying the PRO measures and/or domains of interest; qualitative interviews to tailor PRO report content; playing a visible role in the initial roll-

out of the measures in practice; and undergoing the training necessary to understand what scores mean and how they can be used in the clinical care setting.

Finally, most systems identified a need to demonstrate value to their own institution. All systems require considerable staffing (e.g., IT professionals, clinic staff, providers) that can be difficult to fund and sustain solely from research grants. A key element to developing PRO assessment and ultimately gaining sustainability for many of these projects is a focus on identifying and "proving" value. Value can be procured through a reduction in staff hours, higher quality of care scores or receipt of incentive payments and increased billing (e.g., automated referral, or other methods).

Theme 4: EHR Integration and Limitations

The case studies show the wide applicability and usefulness of PRO data. They include a range of medical disciplines, age groups and locations (hospital, health plan, state, and region). For each of these groups, specific considerations were identified to ensure PRO collection was useful and relevant to specific clinical situations. However, scaling-up PRO use raises new considerations related to action-item "ownership". In other words, how PRO information collected for a patient across different clinical encounters is presented as actionable items to various providers matters. For example, ownership would increase the likelihood that issues that are not commonly addressed in specialty care (e.g., a patient's mental health and social functioning) are in the patient's record and flagged for specialists. Conversely, primary care clinicians will be presented with PRO information for a wide range of conditions and situations pulled from specialist visits. PRO information may be available to the care provider. Further consideration is needed on how the same scores can be used across providers with different training and disciplines to inform the treatment of medically complex patients.

Most systems consider these issues based on their own needs and perspectives. Group Health provides only "basic" PRO information about physical and mental health, focusing on gathering other patient-reported information (smoking, diet, exercise) that can inform preventive care and educational recommendations. Some systems (Cincinnati Children's and UPMC) consider this issue by evaluating and reducing patient burden where possible. Methods to accomplish this include ensuring that patients with

multiple conditions are given a limited number of surveys: utilizing “aggressive” skip patterns in an effort to tailor the experience to relevant content, or programming survey assignment indexed against the last completed assessment, rather than last visit date. This ensures surveys are not re-administered if a patient has multiple appointments within a short window of time. More research is needed to consider conceptually how to identify and assess complex patients and how this information can be used to inform their care with the least amount of burden to the patient, provider, and system.

MOVING AHEAD

The individual case studies presented above combined with the synthesis of themes across the case studies are instructive in considering how to promote the integration of PRO data in EHRs more widely. One advantage of PRO methods is their ability to capture the patient experience in a standardized, systematic way with established reliability and validity (Acquadro 2003; NIH 2009). This is important for PRO measures to be useful for clinical practice, for quality assessment and improvement and for research. However, as described above, there is a diversity of approaches to integrating PROs in the EHR, including measure selection, mode of administration, analysis, results reporting and interpretation, data access and models of governance.

Standardization of EHR-based PRO measurement could provide benefits for both research and quality assessment, in addition to use in the care of individual patients. Scores on standard PRO measures could be pooled across different institutions for various uses including comparative effectiveness research, or to compare the outcomes obtained by different providers both within and across institutions. Comparing outcomes across institutions could be particularly useful in calculating information about the value of care.

To accomplish this kind of standardization, harmonizing efforts are needed on multiple levels. Certainly, there should be coordination within individual organizations, which should avoid using different PRO measures to capture the same concepts when possible. This will need to be done thoughtfully given the trend for large health care organizations to acquire other hospitals and practices. At the next level, standardization efforts could focus on provider groups, integrated delivery systems, health plans, city-

wide or state-wide health information exchanges and regional health information organizations. At each level, various degrees of standardization may be required to ensure that PRO measures are collected, shared, and retrieved in a meaningful way. The standardization efforts should ensure that similar PRO measures are available across organizations, and the results are interpreted similarly. Professional societies and organizations focused on specific disease conditions should also consider standardizing methods. This has already been done with success by several national and international organizations such as the American Urological Association which has embraced the IPSS (International Prostate Symptom Score)(Cockett 1991; USLI 2012) and the IIEF (International Index of Erectile Function)(Rosen 1997), the National Eye Institute which developed and promoted the use of the National Eye Institute Visual Functioning Questionnaire (NEI-VFQ) (Mangione 1998), and OMERACT (Outcome Measures in Rheumatology) which strives to identify, endorse, and improve health outcome measures (http://www.omeract.org/).

Market forces may result in a certain degree of standardization as well. The consolidation of the market for large EHR systems is playing a role in consolidating PRO measures. For example, the Epic MyChart includes several built-in PRO measures, which are administered to patients online in the same manner for all installations of Epic. However, even in this case, there is a proliferation of measures that are developed and deployed using other third-party systems and integrated to different degrees within the Epic EHR.

Conceptual System Architecture

A conceptual system architecture diagram may be useful to help understand and guide standardization that will enable high-quality data and the ability to "measure" once within EHRs to collect and store PRO data, and "cut" multiple times for different uses across clinical, quality improvement and research applications (Figure 4).

Electronic data repositories of PRO measures are collected and stored in different systems such as: tethered EHR-based patient portals (e.g., MyChart), standalone patient portals (e.g., Microsoft HealthVault), standalone PRO web tools (e.g., Cleveland Clinic Knowledge Program, PatientViewpoint, commercial data collection systems),

digitized data from local paper-based PRO data collection, Computerized Adaptive Tests (CATs) (e.g., local Patient-Reported Outcomes Measurement Information System (PROMIS)(Cella 2010)), and multi-center provider/payer PRO research data collection systems (e.g., REDcap).

These various dispersed PRO repositories are currently not connected through health information exchange initiatives. Health information exchanges collect, aggregate and share specific clinical data across multiple different electronic health records/providers; however, they generally do not include the data captured in EHR-based patient portals (i.e., where PROs are collected) due to the lack of standardization and low prioritization by providers. As a practical matter, health information exchanges do not collect data from non-EHR repositories such as standalone web tools, research databases, and population health datasets.

In an idealized system architecture, health information exchanges would develop separate or embedded technical layers that collect, map, aggregate, store, retrieve and analyze different sources of scattered PRO data for specific goals. In this framework, data elements that are captured in patient portals can also be shared for other research/clinical purposes. This general storage/analytic layer could be called the "population health layer" which includes the capacity to handle PRO data in a standardized way.

Unanswered Questions

Achieving the ideal system described above for PRO integration both within and across EHRs will require both broad efforts for implementation and standardization, as well as investigation of a number of unanswered questions (Table 2). These questions can again be organized based on the different aspects of integration of PROs in EHRs. Many of these gaps in knowledge could be addressed by targeted requests-for-proposals from PCORI, ONC, or other funding agencies.

Table 2: Knowledge Gaps in Integrating PROs in EHRs

Integration Aspect	Question
Selection	Can the same PRO measures be used for clinical care, research and quality improvement?
	How should organizations prioritize among PRO measures?
	What is the place of proprietary PRO measures in EHRs?
Administration	What standards should be recommended for PRO collection?
	What metadata should be collected with PRO measures?
	How can missing data be reduced?
Reporting	What is the impact of standardizing interpretation?
	Is there equivalence among different PRO language versions?
Analysis	What risk adjustment is needed for PRO outcome measures?
	What are the best strategies for handling missing PRO data?
	Can a standard set of items be used to calibrate a series of PROs?
	Can automation accurately auto-populate clinical fields?
	How much IT professional time is needed to generate reports?
	How much IT professional time is needed to extract datasets ?
Access/Security	When should PRO data be available in the clinical record?

(1) Selection

For all purposes, a PRO measure should meet basic standards of reliability, validity, responsiveness, and interpretability of the measure in the intended population. A number of guidelines have been published regarding these standards in the last few years (Brundage 2012, Mokkink 2010, FDA 2009; Scientific Advisory Board MOT 2002; EMA 2012; Snyder 2011). There are also catalogs of PRO measures, such as the Patient-Reported Outcome & Quality of Life Instruments Database (PROQOLID), a searchable, curated library of measures, with references and contacts (MAPI 2013).

Should the same measure be used for multiple purposes? It would be most efficient to measure once and apply the same score for multiple purposes (Wu 2013). However, there are differences between the ideal PRO measure for practice and for research. The former might be parsimonious and directed towards actionable domains, while the latter might maximize measurement precision to reduce needed sample sizes. Additional questions include: Are existing PRO measures designed for research suitable for clinical practice? How useful are generic measures in disease-specific studies?

How should health care organizations prioritize among PRO measures for implementation? For clinical practice, a PRO measure should be acceptable to clinicians, and its results should be interpretable and actionable (Snyder 2011). At the start, selection in some clinical specialties may be easy, since there are a few measures that are already widely used or endorsed by professional societies, such as the urology examples mentioned previously. Aside from these, there is a lack of PRO measures that provide good interpretation for clinical use. PRO measures that can be easily misinterpreted (e.g., due to measurement error or poor face validity) could result in confusion, and limited clinician buy-in. Therefore, these measures should be avoided. Perhaps developing a standard group of PRO measures with add-ons for research and quality improvement could address these concerns. This kind of rationalization would also shorten the work queues of over-burdened IT professionals.

For research use, there is a greater diversity of PRO measures. Investigators may want to use measures that are highly specific to a particular research question. It may be most efficient for these data to be collected using an organization's patient portal and EHR. In multicenter clinical trials and observational studies, there may be a centralized selection of PRO measures to be used. However, as some of these measures may never have been used in clinical practice, to maximize safety, it would be desirable if the results were only visible to investigators. For use as a quality improvement tool, a PRO measure needs to be situated within a specific context (NQF 2012b) to create what the National Quality Forum refers to as a PRO-PM (PRO Performance Measure).

What is the place of proprietary PRO measures in EHRs? A practical consideration is whether permission and payment are required for the use of a selected PRO measure. There is a charge for use of some of the most widely used generic PRO measures, such as the SF-36 (Ware 1992), the Health Utilities Index (HUI-3) (Feeny 2002) and the EQ-5D (EuroQol 1990). Health care organizations and EHR vendors are concerned about delays to the implementation of their systems and several have elected to use PROs that are available in the public domain, such as the PHQ-9 (Kroenke 2001) for depression screening. Some publicly available versions are nearly identical to proprietary tools, such as the RAND-36 (Hays 2001) or the VF-12 rather than the SF-36v2 or the SF-12v2 (QualityMetric 2013 a,b). There is also a movement to practice

“copyleft”, in which a PRO measure is copyrighted and then made available for public use free of charge (Heffan 1997).

(2) Administration

A major distinction can be drawn between PRO data collection using a tethered portal (e.g., Epic MyChart) versus using an internet connected or freestanding device that delivers data to the EHR (Kharrazi 2012).

What standards should be recommended for the collection of PRO measures?

To achieve acceptable data quality, it may be desirable to recommend standards for the collection of PRO measures. This is analogous to instructions for obtaining a blood sample for a lipid profile accompanied by the instruction or query if the patient was fasting at the time of collection. In the case of PRO measures, instructions may be general, such as “complete before the next clinic visit", or "complete without assistance".

What metadata should be collected in association with PRO measures? If it is likely that the instruction for administration may not be followed (e.g., complete questionnaire without assistance), an item can be added to capture whether the instructions were followed, as is done at the Cleveland Clinic. This kind of metadata can aid with interpretation (Pearcy 2008). For quality improvement, it can help to determine if the data are eligible to be included in a performance measure. This information is particularly helpful if data are to be aggregated and compared across different treatment settings or organizations.

How important are missing data and what should be done about it? Missing data and lack of follow-up are particularly problematic if the PRO data are to be used on a population level to answer research questions. They are also important if the data are to be used to determine the effectiveness of treatment for individual patients. To address this problem, provision can be made to send patients reminders or to add supplemental modes of data collection (e.g., Interactive Voice Response) of data collection. A related problem is the phenomenon of “hidden” data, which represent events that occur but are not recorded. An example of this is a dip in a patient’s mood that occurs between clinic visits and is not captured. More work is needed to determine how modes of

administration affect data completion – e.g., the effect of different strategies allowing missing responses, defaulting a response that patients can change if desired: including fewer or more questions per screen, or allowing patients multiple log-ins per session? If data are truly missing, analytic solutions are needed to handle those missing data.

(3) Reporting and Interpretation

Clinicians often complain that it is difficult for them to understand the meaning of PRO scores. The display of PRO score results can be annotated to identify levels of dysfunction or impairment that may signify the need for clinical intervention (Snyder 2010). This is analogous to the common practice within most EHRs to highlight laboratory values that signify out of the normal range (e.g., a serum potassium of 6 would be highlighted in yellow). For a given population, it may be desirable to standardize the cutoff score, such as which score on a pain scale represents a level of distress that warrants action. For clinical purposes, it is important to designate what cutoff indicates a "panic value" that would require immediate action. An example would be a positive response to a PHQ-9 item indicating suicidal ideation, which would require a timely response.

What is the impact of standardizing interpretation, e.g., cutoff scores? Although there would be obvious benefits for researchers, some systems (eg., My GI health) offer a very different perspective. They let providers set their own cutoffs with the idea that they will adapt it to their needs over time. There are likely to be benefits to this approach, such as clinician buy-in. However, research will be needed to see how it compares to more standard methods of establishing statistical cutoffs.

Is there equivalence between different language versions of the same PRO measure? US society is rapidly becoming more multicultural, and research studies have evolved to include larger networks of sites, including international observational studies and clinical trials. Therefore it is increasingly important to determine if the translated and culturally adapted versions of a given PRO measure are equivalent to one another, and if data from the two versions can be pooled (Herdman 1997, Wagner 1998). Research is needed both to test this premise and to determine optimal ways to harmonize the development of PRO measures in multiple languages.

(4) Analysis

The analytic methods applied to PRO data will vary based on the purpose for which the data are collected, as well as the specific questions being posed. For all purposes, standardized scoring algorithms are available for most PRO measures. However, beyond this, there are many practical and methodological questions to be answered regarding the analysis of PRO data. For clinical purposes, estimation methods, such as in the use of a PRO measure as a screening test, may be required. For research and quality improvement, there is the following question:

What risk adjustment is needed for PROs used as measures of process or outcome? For research and quality improvement, risk adjustment methods may be needed. As noted above, it may be useful to have metadata elements such as location where completed (at home vs. in-clinic), mode of administration (telephonic vs. electronic) or completion with assistance (completed by surrogate vs. translated by interpreter vs. completed by a family member) to incorporate into the analysis of data. These data would help researchers generate evidence of the validity and responsiveness of PRO measures under different conditions. Metadata can also help identify the unit of analysis and contribute to risk adjustment.

What are the best strategies for handling missing data? Missing data on patients' health related quality of life are likely to be informative in studies of treatment effectiveness. However, although there are a number of approaches in use, there is no consensus on the best strategies for imputing or otherwise handling missing PRO data (Fairclough 2008, 2010). It is possible that the collection of metadata could help to estimate scores. There are also novel modeling methods based on data mining and Bayesian network modeling that might be considered. Research is needed in this area.

Can a standard set of items or measures be used to calibrate a series of PRO measures? If this can be accomplished, then it would be possible for a PRO questionnaire to be customized to specific uses, but for the results still to be pooled with the results from other questionnaires to which scores have been calibrated in a known manner. One NIH-funded effort, dubbed the "PROsetta Stone," uses the PROMIS T-

score metric (a score of 50=the US mean, 10=1 SD) to compare PRO scores from different questionnaires (Cella 2011, Choi 2012, Choi in review, Schalet in review). Previous smaller efforts have identified how a similar method can convert scores collected using one questionnaire into comparable scores for a different related measure, to be compared or combined (Wu 2005; Chan 2011). If this is possible, it might support the universal use of a set of common core items and scales with known relationships to larger families of scales.

In addition, there are a number of practical questions to be addressed, such as *to what extent can automation be used to accurately auto-populate fields and generate reports? How much IT professional and data manager/analyst time are needed to generate reports and extract datasets?*

(5) Access, Confidentiality, and Security

Data availability, confidentiality and security are growing concerns in society at large as well as in health care. For clinical purposes, the data in an EHR are generally accessible to all health care workers with an individual logon to the system, but only permitted on a need-to-know basis for members of a patient's care team. These rules are enforced by the built-in capacity to monitor who views any data element. One question to be addressed by health care organizations is:

When should PRO data be made available in the clinical record? The desired accessibility to PRO data may vary depending on whether the data are used for clinical care, research, or quality improvement. For both clinical care and research, there is an option within some PRO systems to control whether to "release" a specific piece of information from the patient portal to the EHR. For research, should a separate consent procedure be required? For quality measurement, some PRO data (e.g., patient satisfaction surveys) should only be available to individual providers on an aggregate basis? Research is needed on the ethical and practical aspects of these issues.

Key Barriers and Enabling Factors

It is possible to summarize a number of modifiable as well as less-modifiable barriers to incorporating PRO measures into EHRs from the perspective of the patient, the clinician,

and the health system. They include a wide range of concerns: PRO collection and reporting; the clinical environment and engagement. Some of these concerns echo themes that have been noted for decades (Deyo 1989). It is also possible to identify potential enablers that could be implemented or developed to help overcome the more modifiable barriers (Table 3).

From the patient perspective, there may be a lack of awareness or understanding of the importance of the formal measurement of PROs. However, it is not difficult to convince patients that it is important to communicate their experience and point of view to their physician(s). The best ways to increase awareness have not been identified. However, the concept of systematically asking patients to report their outcomes can be empowering.

System promotion and branding was an unexpected enabler found in our review. Systems that invested in a branding, through establishing a system name, easily accessible online materials and even the occasional YouTube video, supported other enabling factors and addressed engagement barriers. A memorable name helps patients to remember and log-on, increases awareness for interested clinicians, and provides advertising and promotional opportunities.

Health literacy can be a barrier to understanding and responding to questions in a PRO measure. A partial solution is to assure that PROs are available at low reading levels. A second approach is to make PRO data collection available through several different channels, including by telephone. In the US, people whose first language is not English may need PROs in their native language. This requires that translated and culturally adapted versions of a PRO be available and tested for a wide range of languages. Despite the increased availability of internet service not all individuals have access to the internet and internet access may be most limited among disadvantaged populations. To achieve greater participation in PRO data collection, multiple options for data collection are needed including both electronic (e.g., web and cell-phone based) and others. Studies are needed to demonstrate the equivalence of different modes of administration (Kongsved 2007; Coons 2009).

Table 3: Barriers to Incorporating PROs in EHRs for care, research and quality

BARRIER	MODIFABLE	ENABLERS
Patient		
Lack of awareness	+	Explanation, empowerment
		Effective branding and marketing
Health literacy	+/-	Tailor PROs to lower reading level
Language barrier	+	PRO Translation/cultural adaptation
Lack of internet access	+/-	Multiple options for collection
Lack of engagement	+/-	Feedback results & recommendations
		Communication training for clinicians
		Active follow up
Time constraints	+/-	Computer adaptive tests
		Improve capacity for branching logic
Clinician		
Time constraints	+	Redesign work flow, use extenders
		Design-in time savers
		Financial incentives
Desire for single login	+	Full integration of PROs into EHR
Lack of familiarity	+	Just-in-time information support
		Clinician education/training
Negative attitudes	+	Local clinical champion
		Promote clinician innovation
		Provide disease specific PROs
		Institutional leadership support
		Professional society support
Lack of self efficacy and outcome expectancy	+	Recommend actions to take
		Improve PRO integration in reports
		Identify best practices in data display
System		
Lack of IT workers	+/-	Training clinicians to program
		Support IT workers from research
		Select standard measures
Proprietary PRO tools	+	Negotiate large scale contracts
	+	Use public domain PROs
Difficulty pooling data	+	Standardize cross site data collection
		Promote calibration
Missing research data	+/-	Collect metadata
		Develop data imputation strategies
Wi-Fi not universal	+	Support Wi-Fi infrastructure
Limited data exporting	+	Improve integrated software tools
Limited designer understanding of IT	+	Work in multidisciplinary teams
Integration is > Epic	+	Development of additional systems
Informed consent		Develop acceptable opt in/out strategy
		Consent outside the clinical workflow

Many patients are not sufficiently engaged in their own health care, including signing up for patient portals and completing PRO measures for clinical use. Research is needed to demonstrate effective methods for engaging patients with PRO data collection. Currently, promising methods include feeding back to patients their individual results and providing actionable recommendations. Active follow-up methods may be needed to achieve satisfactory rates of completion, especially over periods of time. Training clinicians to discuss PRO results with patients is also associated with increase patient enthusiasm for filling out PRO questionnaires. Although completing PRO questionnaires takes time, patients who are convinced of their value will be willing to invest greater amounts of time. PRO data may be completed more efficiently using CAT (Reeve, 2007) and if systems incorporate branching logic to help individualize the selection of instruments.

From the clinician perspective, any task that requires additional time will be met with resistance. A key research question is how PRO data collection can be incorporated into the clinical workflow of a busy practice. Potential solutions include delegating some of the work involved to other providers and building in time savers such as the capacity to auto-populate clinical notes with patient responses to PRO questions. Clinicians have an aversion to logging in to multiple systems, a problem that can be solved by full integration of PRO measures into EHRs. A different type of solution is to provide incentives for using PRO data, such as pay-for-performance.

Lack of familiarity with PRO measures and what to do with them can be remedied by providing education and training of practitioners, including during pre-clinical education such as medical and nursing school. Especially in the short-term, just-in-time support, analogous to other types of clinical decision support, may be the most efficient methods of explaining the meaning of PRO scores and relevant interpretations in clinical care settings. Clinician skepticism and other negative attitudes to PROs may be overcome by the presence of a clinical champion in the clinician's own discipline. These individuals can demonstrate and promote the use PROs and facilitate active discussion of their utility in clinical practice. The use of disease-specific PROs and reporting of item-level patient responses may increase the salience of measurement to skeptical specialists. Professional societies and institutional leaders can also help to establish

the importance of PRO data by encouraging and promoting their use. Lack of self-efficacy and outcome expectancy can be addressed by recommendations of action to take in response to the question “what can I do?” (Hughes 2012) or prescribed sets of actions (MNCM). Improved PRO integration in EHR data displays, whereby PRO data can be charted against other clinical data, can also increase understanding of patients’ progress over time and the relationship to treatment. Improved data report features can also help clinicians to appreciate the PROs experienced by individuals and groups of patients. Research is needed to design and test different approaches to gaining the acceptance by clinician of PRO measures, as well as the necessary supporting resources.

From the system perspective, perhaps the most obvious barrier to PRO integration is that it competes for the time of IT professionals who are already busy with other responsibilities. This represents a bottleneck in organizational workflow, particularly for those that are in the process of adopting new EHR systems. One solution is to decrease the demand by prioritizing a few standard PRO measures. An alternative solution is to increase the supply of staff available to help with PRO integration. This could include researchers and even clinician enthusiasts who can assume some of the work of designing PRO workflows. Since many PROs will be used primarily for research, it is also reasonable to train and support the time of additional IT professionals using designated research funds. Larger organizations may choose to do this centrally.

In the interests of avoiding hassles and expense, some systems and organizations have chosen to avoid the selection of proprietary, albeit well-tested, PRO measures in favor of those available for free in the public domain. An alternative strategy would be to select a few proprietary measures and negotiate agreements for a large number of users. Large health systems may be in the best position to do this.

Researchers, particularly those conducting multi-site studies, face the challenge of pooling data collected at multiple sites using different collection methods. Ideally they would like to have standardized methods of data collection across all of their different sites. There is a compelling argument for standardization across the multiple phases of

PRO data use. An alternative solution is the calibration of different PRO measures that share these core items, as noted in the previous section. Additional work is needed in this promising area.

There are additional technical barriers related to the collection and handling of PRO data. An unexpected barrier identified was problematic Wi-Fi coverage. Hospitals, for example, may have limited network capabilities, reception, or only offer "guest" network access that may have limited security protocols. Rooms themselves can limit reception (e.g., basements or shielding). All these considerations can limit capturing PRO data, especially when using hand-held, web-based collection. An obvious but costly solution is to of increase availability of Wi-Fi. Another is the as provision of multiple modes of data collection. Limits to the easy exporting of data to create analytic datasets is a problem best addressed by EHR vendors. The finding of limited understanding of health IT by PRO designers should not be so surprising given the complexities and rapid developments in EHR design. An enabler noted in our cases is the presence of a multidisciplinary team to help address local measurement, system and integration knowledge gaps. A current issue is the observation that virtually all of the systems that we found used or interfaced with the Epic system. Although other EHR vendors may incorporate PRO integration to some degree, these efforts are relatively limited. The current state of the market could potentially reduce innovation (Shaywitz 2012). There is certainly the opportunity for other EHR vendors to develop competing systems.

A final category of barriers faced by organizations and systems is those related to requirements for informed consent for research participation, and the practical aspects of incorporating these requirements into the clinical work flow. We will not discuss current discussions for need for consent for data that are collected for quality improvement and those that are collected for research (Kass 2013; Faden 2013). Potential solution include designing improved methods to identify patients willing and unwilling to participate in research and moving consenting procedures outside of the workflow entirely.

CONCLUSION

The fields of PRO measurement, EHRs, and comparative effectiveness research have converged to a space that is more patient centered and more electronically based than ever before. There is the potential for patient portals connected to the EHRs to provide a useful platform for computerized PRO measures. PROs are inherently different than laboratory values and the other structured data elements already captured in the EHR. The EHR is pivotal point at which all of these are data are integrated to be used for different purposes. If system designer fail to plan PRO collection so that it accommodates the needs of patients, if they employ PRO measures with inadequate reliability and validity, if they are not mindful of clinical workflows, or the PRO data are not presented clearly, then usefulness will be compromised.

This report suggests that current electronic PRO systems within EHRs vary significantly in their focus and features. All of the systems consider key factors for sustainability and expansion, as well as how system features shape current EHR integration capabilities. The diversity in goals and design provides the opportunity for best practices to emerge in the early stages of PRO implementation within the EHR. It is also evident that lack of standards and standardization in itself poses a practical and financial barriers to large-scale PRO collection and reporting. Recent development, from low cost computer hardware to the expansion of PRO collection capabilities to tethered patient portals, provide an opportune time to intervene and align various stakeholders to harmonize PRO measures in the EHRs for clinical use and, more broadly, for comparative effectiveness research. Coordinated research and educational efforts are needed to ensure PRO integration is done in a way to ensure the accuracy and accessibility of PRO data available in the EHR for all interested clinicians, researchers, and patients.

In the future, it will also be important to understand the features and mechanisms that promote the systematic and useful capture of the patient perspective in care, quality improvement and research. There is currently a lack of evidence regarding many scientific and practical aspects of implementing PRO measures in EHRs. Many of these gaps in knowledge could be narrowed by targeted requests-for-proposals from PCORI and other funding agencies.

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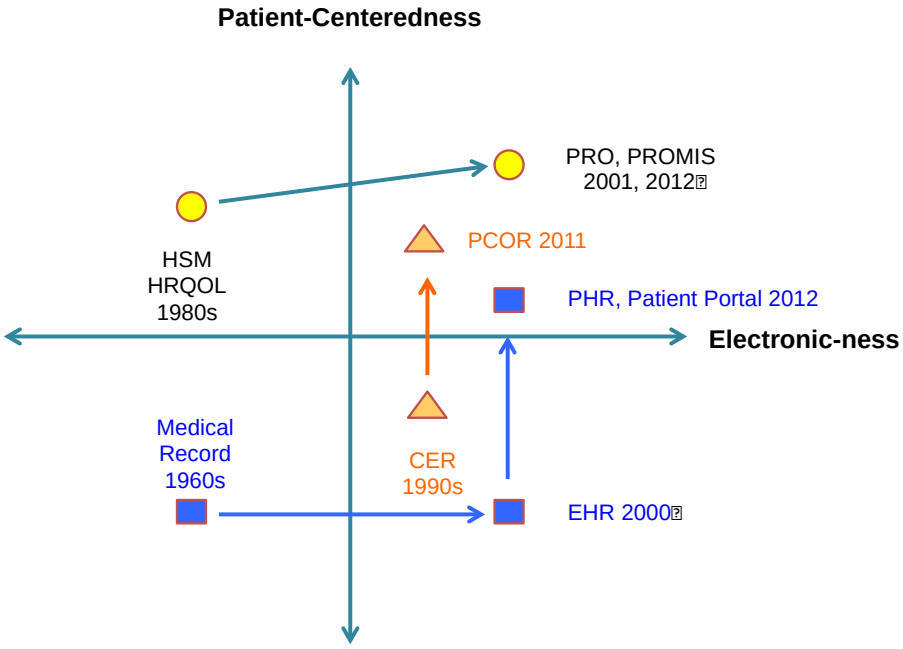
FIGURE 1: The convergence of patient-reported outcome (PRO) measures, electronic health records (EHR) development, and comparative effectiveness research (CER) *(adapted from Wu AW, Kharrazi H, Boulware LE, Snyder CF. J Clin Epidemiol. 2013.)*



HSM=Health Status Measurement
HRQOL=Health Related Quality of Life
PRO = Patient Reported Outcome
PROMIS = Patient-Reported Outcomes Measurement Information System
PCOR=Patient Centered Outcomes Research
PHR=Personal Health Record
CER=Comparative Effectiveness Research
EHR=Electronic Health Record
Circles indicate measurement of PROs
Triangles indicate the comparative effectiveness research field
Squares indicate the predominant forms of medical records

FIGURE 2: Model for Using Patient-Reported Outcomes in Quality Assessment and Improvement (*Snyder C, Wu A. Patient-Reported Outcomes and Care Quality: Intervention? Outcome? Adjuster? Presentation to Centers for Medicare and Medicaid Services Measure Forum. January 17, 2013.)*

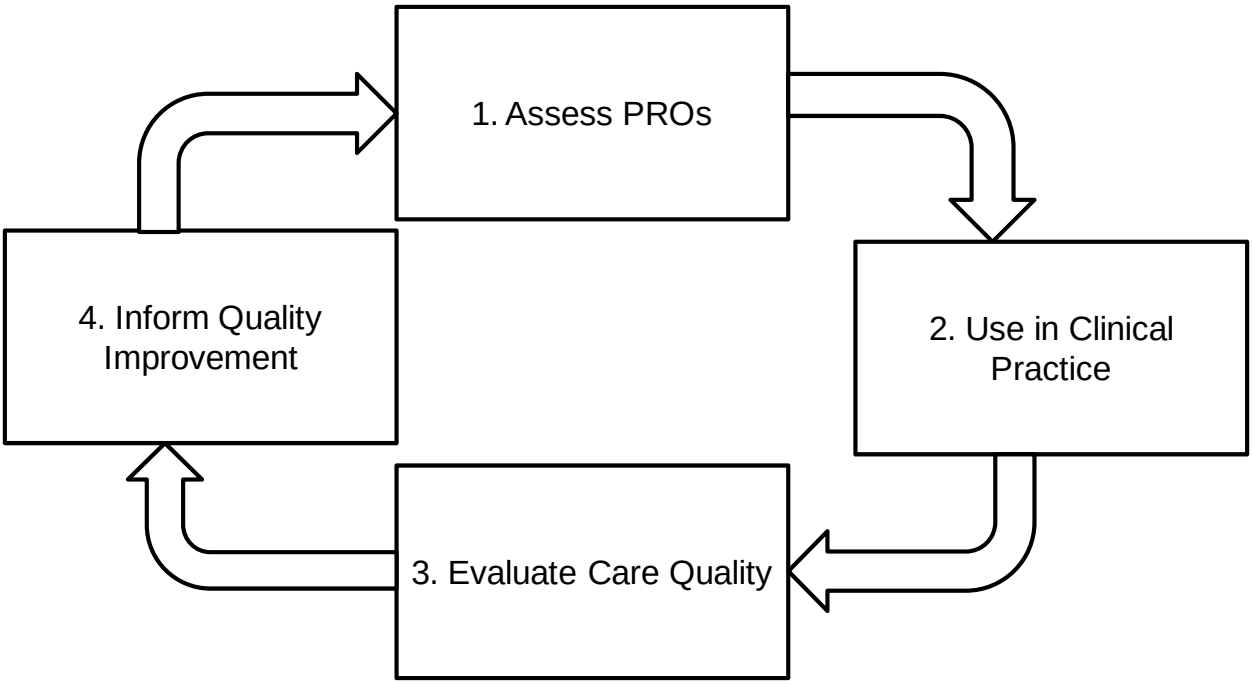
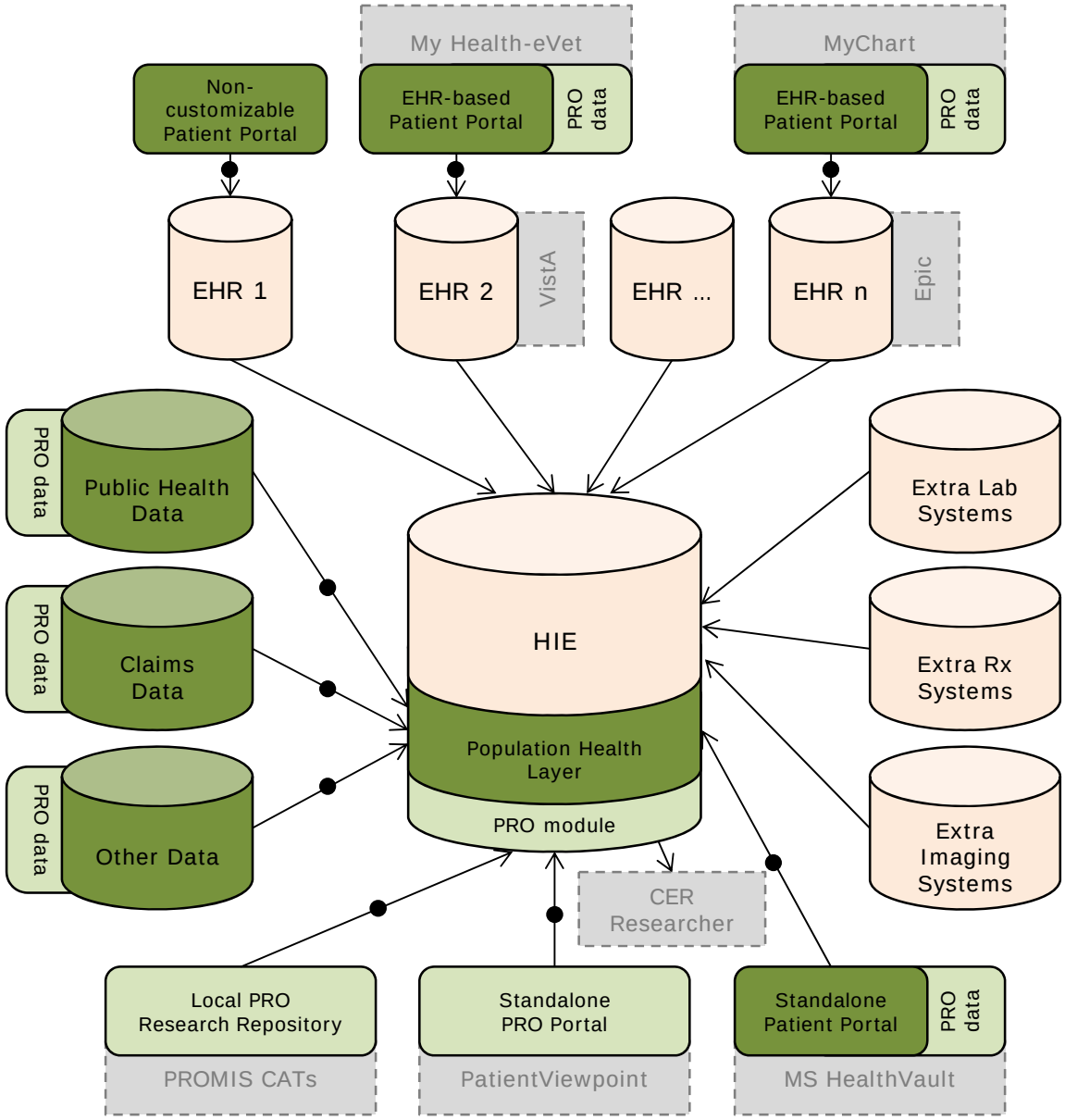


FIGURE 3: Idealized conceptual system architecture for an interoperable city/ state/ region/ national HIE-based PRO platform for multiple uses *(adapted from Wu AW, Kharrazi H, Boulware LE, Snyder CF. J Clin Epidemiol. 2013)*



EHR=Electronic Health Record
PRO=Patient Reported Outcome
HIE=Health Information Exchange
CAT=Computerized Adaptive Test
PROMIS=PRO Measurement Information System
Orange: Typical HIE data sources
Dark green: Population health data sources
Light green: PRO data repositories
Light gray/dashed border: sample systems
Arrows to middle silo: PRO messaging standardization required.

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