Using Patient-Reported Information to Improve Health Outcomes and Health Care Value:

CASE STUDIES FROM DARTMOUTH, KAROLINSKA AND GROUP HEALTH
Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health

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The Dartmouth Institute for Health Policy and Clinical Practice

The Dartmouth Institute is part of the Geisel School of Medicine at Dartmouth and Dartmouth College. The mission is to measurably improve health and health care through research, education and engagement with the vision of a sustainable, patient and family-centered health care system committed to a healthy population. The Dartmouth Institute has more than 200 faculty and staff who lead: (a) graduate and professional education programs, (b) research programs to advance measures of health outcomes and costs and to track the performance of the US health system, and (c) the implementation of programs to improve practice and health systems.

The Medical Management Centre at the Karolinska Institutet

The Karolinska Institutet is a Swedish medical university, founded in 1810. The mission is to contribute to the improvement of human health through research and education. Karolinska Institutet accounts for more than 40 percent of the medical academic research conducted in Sweden and offers the country’s broadest range of education in medicine and health sciences. Since 1901, the Nobel Assembly at Karolinska Institutet has selected the Nobel laureates in Physiology or Medicine. The vision of the MMC is to address how resources in the form of competence, knowledge, material and other assets can best be used and developed to improve human health. MMC also offers academic education to undergraduate programs and health care professionals and managers, and carries out research to support a science-based management practice in health care.

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Group Health Research Institute's mission is to improve health and health care for everyone through leading-edge research, innovation and dissemination. Founded in 1983, GHRi is a nonproprietary, public-interest research center within Group Health Cooperative, an integrated health care system located in the US Pacific Northwest. The faculty includes about 60 health scientists, including physicians, epidemiologists, biostatisticians, psychologists, economists and health services researchers. GHRI shares its findings primarily through articles in peer-reviewed medical journals, presentations at scientific meetings, and the media.

Dartmouth-Hitchcock

Dartmouth-Hitchcock is a national leader in patient-centered health care and building a sustainable health system. Founded in 1893, the system includes New Hampshire’s only Level 1 trauma center and its only air ambulance service, as well as the Norris Cotton Cancer Center, one of only 40 National Cancer Institute-designated Comprehensive Cancer Centers in the nation, and the Children’s Hospital at Dartmouth-Hitchcock. As an academic medical center, Dartmouth-Hitchcock provides access to nearly 1,000 primary care doctors and specialists, as well as world-class research at the Audrey and Theodor Geisel School of Medicine at Dartmouth.
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We hope you enjoy reading this paper and discover, as we did, the many ways that patient-reported information—the voice of the patient—can be used to provide higher quality care to reduce the burden of illness, prevent disease, and promote better relationships between patients and doctors.

Today, we find that for patients to recover faster and improve their health, it is essential that the clinician has clear and accurate pictures of how the patients are feeling, how they are limited because of their health, how they are suffering, and what their expectations are of their doctors (or health team) to make them feel better. One important gauge of a successful treatment is to turn what the patient says into measures of physical function, mental health and symptom severity in ways that really matter to patients. Can the patient do more? Is the patient feeling better?

In addition, we want our doctors not only to reduce the burden of illness but also to help the patient avoid illness, prevent disease, and promote health and well-being. Therefore, we want to make it easier for patients to partner with their health teams to avoid illness and injury, and to make it possible to live longer and healthier lives. For this health-promotion partnership to work, it is necessary to know what the avoidable health risks are for the individual, what can be done to reduce these risks, and how the patient can become engaged in taking preventive measures to live a healthy life, full of vitality.

Prevention needs to be fueled with data and information that can only come from asking patients questions about their habits and lifestyle, and turning these answers into information that shows the level of health risk, and whether it is increasing or decreasing over time.

Patients want to have a good relationship with their health professionals and this requires good communication about what matters most to them, as well as developing a sense of trust and caring as time passes. We have seen that it is possible to enrich communication between patients and doctors by transforming the voice of the patient into information that is meaningful and actionable, and thereby improve both patient-clinician relationships as well as the health outcomes that matter most to patients.
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This paper aims to:

a. demonstrate the utility of using patient-reported measurement systems to improve health care outcomes and value,

b. illustrate the feasibility of using patient-reported measurement systems in typical clinical settings, and

c. discuss some of the lessons learned about patient-reported measurement systems based on case studies.

We present three case studies. The first describes the Dartmouth-Hitchcock Spine Center located at Dartmouth-Hitchcock Medical Center in Lebanon, NH, and a related comparative-effectiveness research network. The second highlights the Swedish Rheumatoid Arthritis Registry based at the Karolinska University Hospital in Stockholm. The third case summarizes the electronic health risk assessment system developed by Group Health Cooperative in Seattle, WA, to support prevention and chronic illness care for patients and primary care clinician teams.

Patients and clinicians have generally favorable reactions to the patient-reported measurement systems in these real life implementations. Both stakeholders believe that it provides important information to support patient-centered care by focusing attention on the health issues and outcomes experienced and desired by patients. Both patients and clinicians also report that using patient-reported measures takes extra time for data collection but that it makes the care more effective and efficient by enabling the clinician to focus quickly on the patient’s current health state – disease status, functional status and risk status.
The utility and feasibility of using patient-reported measurement systems are demonstrated by their sustained use in these three very different health systems. Experience shows that successful patient-reported measurement systems are based on a set of design principles including:

a. fitting the patient-reported measures into the flow of care and using the data to make it easier for clinicians to do their jobs and for patients to engage in self-management, make informed decisions, and draw attention to the outcomes they value most,
b. co-designing the patient-reported measurement system with stakeholder engagement,
c. engaging with patients and clinicians about how to use the patient-reported measures,
d. merging patient-reported measurement data with data from other sources (clinician reports, medical records, claims) to leverage the utility of the patient-reported measures, and
e. continuously improving the patient-reported measurement system based on users’ experiences and new technology.

CONCLUSION: A promising way to improve health care value is to embed information provided by patients into the flow of clinical care using patient-reported measurement systems. The health of patients and populations can be improved, and the value of care can be enhanced, by taking advantage of patient-reported data within the clinical context.
INTRODUCTION

BROAD CONTEXT: NEED FOR VALUE IMPROVEMENT

The primary aim of modern health systems is to produce optimal health outcomes (risk status, disease status, functional status) for patients and populations and to deliver services that are of the highest possible quality (safe, timely, equitable, effective, efficient, and patient-centered)1 and to do this at the lowest total cost to consumers and payers2 without compromising those outcomes and services. In short, the aim is to improve the value of the product produced by health systems where value can be defined as health outcomes and health care quality in relationship to total health care costs over time.

To determine the extent to which value is realized and to identify ways to improve care, we need to measure health outcomes for both individual patients and populations using health information technologies that:

1. capture patient-reported data and feed this information forward to all clinicians caring for a patient, in real-time at the point of service, as care is delivered, and
2. feed the data back to patients and clinicians at the individual level, and to employers, payers, researchers and regulators at an aggregate level to reflect changes in health status associated with health care, and
3. provide performance data on the quality of care and services provided to patients and populations.

The challenge is to design and implement information-rich systems that are affordable and practical while they “feed forward” and “feedback” core, patient-reported data on changes in health status to supplement other data on quality and costs.

Figure 1 (opposite page) provides a schematic illustrating the use of patient-reported data in the flow of care to contribute to patient care, program improvement and research. The patient-reported data as well as other core data, drawn from several different data streams (such as diagnostic tests from laboratory systems, administrative data from billing and management systems, and clinician reports from electronic medical record systems).

One fact must be recognized and enabled:

*The preferred source for some core data that is required to measure and improve health outcomes and health care value, is the patient; who is, after all, the primary beneficiary of health care.*

Meeting this challenge is often regarded as an impossible task, but there are already working examples of health information systems that make use of patient-reported data in the way that is needed to make care more effective, more efficient, and more patient-centered.
SHARP FOCUS: PATIENT-REPORTED MEASUREMENT SYSTEMS

This paper will not explore all issues required to create the full and rich information environment that draws data from all the sources cited above (patients, clinicians, diagnostic tests and claims). Rather this paper focuses on using patient-reported measurement systems for the purpose of measuring, improving and researching health outcomes and health care value. The paper will use three case studies, based on work done over the past decade at the Dartmouth-Hitchcock Spine Center, the Karolinska University Hospital and Group Health Cooperative to harness the potential of patient-reported data.

The purpose of this paper is to:

a. demonstrate the utility of using patient-reported measurement systems to improve health care outcomes and value,
b. illustrate the feasibility of using patient-reported measurement systems in typical clinical settings, and
c. discuss some of the lessons learned about patient-reported measurement systems based on case studies.

FIGURE 1

Feed Forward and Feedback Data Flow

Diagram illustrating use of feed forward and feedback data in flow of care for patient care, improvement and research.
1. Feed forward to keep data about the patient with the patient as care is delivered (in multiple settings) over time.
2. Feedback to provide summary data on clinical populations to improve care in individual programs, collaborative networks and to provide research data base.
We believe that this paper is extremely timely. Not only is there a national and international movement to focus attention on outcomes that matter most to patients\textsuperscript{3,4} but effective as of January 2012, Medicare launched a new program for Annual Wellness Visits.\textsuperscript{5} This new program will, for the first time, pay clinicians to provide health promotion services and to work with their patients to develop a personalized preventive care plan. The Annual Wellness Visit requires using patient-reported information on health risks and functional status as a basis for assessing the patient’s health needs and for making a personalized plan of care that’s tailored to the patient’s needs.

The three case studies that follow show the potential for harnessing the voice of the patient to improve health outcomes that matter most to patients and the value of the services that patients receive.
The Dartmouth-Hitchcock Spine Center

CONTEXT AND SETTING
The Dartmouth-Hitchcock Spine Center, based at Dartmouth-Hitchcock Medical Center in Lebanon, NH, opened its doors in 1998. The aim of the Spine Center is to provide one-stop comprehensive care for people afflicted with back and neck problems, a leading cause of morbidity and disability. Dr. James Weinstein and colleagues designed and opened the Spine Center using clinical microsystem principles to plan and manage the program. One fundamental concept used to plan the Spine Center was to collect structured data from patients before each visit that could be used to measure the health status of patients in real-time as well as their expectations for good treatment results. The goals were to:

a. use these data to plan care for each individual patient, based on his or her needs and preferences;
b. use the data for shared decision making between clinician and patient;
c. collect longitudinal patient-reported data to monitor the impact of treatments on individual patients over time; and
d. aggregate the data into clinical subpopulations to be used for program improvement, practice-based research and public reporting.

DATA COLLECTION AND USES
Figure 2 provides a simple flowchart to illustrate the flow of data in the Spine Center and some of its uses. A summary of the flow and uses of the data follows.

**FIGURE 2**

- Patient schedules first visit or follow-up visit to SC*
- Patient reports health data at home or at SC & sends to WH**
- Patient summary report produced by WH
- Patient sees SC clinician & they review current & trended data & make care plan
- SC clinician reports core data on patient and sends to WH
- WH receives, retrieves, stores, manages and analyzes data from multiple sources, including patients, clinicians, diagnostic tests, claims
- WH distributes reports and data displays on individual patients, clinical populations within SC, SC program performance, and comparative effectiveness

*SC Spine Center, **WH Warehouse

Flow of Data in Spine Center and Data Warehouse
Feed Forward Patient Reports
Spine Center patients complete a self-administered 30-minute health survey before each visit. The patient can complete the spine health survey at home, in advance of a visit, using a secure patient portal, or at the time of a visit using a touch pad computer (see Figure 3). In either case, the patient-reported data is immediately analyzed, and displayed in a spine patient summary report, and then inserted into the flow of care so it can be used by the patient, and the clinician/s who are working with the patient, to develop or modify the care plan and to monitor results over time to guide treatment decisions.

**FIGURE 3**

![Patient Completing the Health Survey](image)

Feed Forward Clinician Reports
At the time of the visit, the clinician who sees the patient also enters a small number of core clinical data elements (fixed-field entries on active diagnoses, medications prescribed, and treatments recommended) into a clinical program/research registry and sends the information to the data warehouse.

Return Visits and Follow Up
For each return visit to the Spine Center, the patient repeats the spine health assessment before seeing the clinician/clinical team and the clinician updates/enters the core registry data. This produces ongoing, longitudinal measures of changes in health outcomes (transitions in health status over time) that are associated with the treatments the patient has received. Each new assessment updates the patient summary report showing longitudinal changes in health outcomes; the summary report is used by the patient and clinician/clinical team to review the patient’s progress and to make any desired changes in the treatment plan based on outcomes tracking of patient-focused measures.

Data Trust and Warehousing
The patient-reported data plus the clinician reported registry data are transmitted to a central data warehouse that stores and analyzes the data for all patient visits to the Spine Center. In addition, the data warehouse analysts access and import other data streams, such as patient ratings of their care experience, claims data and diagnostic test results, which enable them to generate feedback reports for defined clinical populations (such as patients with herniated disk and patients with spinal stenosis). It
should also be noted that Dartmouth serves as the analysis center for an NIH-funded comparative-effectiveness clinical trial research program called SPORT (Spine Patient Outcomes Research Trial) and receives anonymized data from 13 spine centers, including Dartmouth-Hitchcock, to provide a database to support this research project. The analysis of this data is discussed below.8; 9

SELECTED USES, ILLUSTRATIVE REPORTS AND DATA DISPLAYS

Patient Summary Report: How is this patient doing?
Immediately upon completion of a patient survey, a clinician can view a summary report, (see Figure 4) including patient responses to the questionnaire, a graphical depiction of health scores over time, a pain diagram filled in by the patient describing what kind of pain is experienced in which locations, red flags based on specialty-specific rules, as well as a listing of the patient’s history, current symptoms, risk factors and the patient’s perceptions of how much treatment has helped. Dr. William Abdu, Spine Center Medical Director, states: “I use this report with every patient I see in clinic to focus our discussion on the important aspects of that patient’s visit.” Dr. Weinstein, founder of the Spine Center and now CEO of Dartmouth-Hitchcock, has testified in national hearings on meaningful use of health information technology (HIT) that: “This patient self-reported summary report is more important to me as a physician than any MRI scan or test. In fact, today it is hard for me to imagine practicing without it. It would be like flying an airplane without instruments.”

FIGURE 4

The Spine Center Summary Report Generated from Patient-Reported Data for Use in Making and Monitoring the Care Plan
**FIGURE 5**

Introduction Webpage for Spine Center on Dartmouth-Hitchcock Public Website

**FIGURE 6**

Descriptive Information for Spine Center on Dartmouth-Hitchcock Public Website
Spine Center Reports: How is the Spine Center Performing?
Data are collected, analyzed, reported and used both to monitor and improve the performance of the Spine Center program and to provide reports to the public on the quality and costs of care. The reports are used by the Spine Center for special improvement projects and for annual retreats to help take stock of past performance and to prioritize improvement opportunities for the coming year. The reports are used by patients, families, consumers and referring providers to obtain accurate information on health outcomes, patient satisfaction, and estimated costs of care, as well as on other topics important to some people such as the number of spine procedures performed in the past year. Some “screen shots” from the Dartmouth public reporting website are provided in Figures 5-7 (opposite page and above).

Comparative-Effectiveness Research:
How effective is surgical care compared to non-surgical care?
Patient-reported data can, under some circumstances, be used for specific research studies. For example, the SPORT (Spine Patient Outcomes Research Trial) has followed several thousand spine patients seen in 13 different centers for more than 10 years. The basic question that SPORT seeks to answer is: what are the outcomes and costs of patients receiving surgical care compared to patients who do not receive surgical care after controlling for case mix differences? Figures 8-10 (pages 20-21) provide summaries of outcome and cost results for three common spine conditions after two and four years of follow-up. All results are adjusted for case mix differences between groups and, of special note, most of the primary results are based on patient-reported data.8,9
FIGURE 8

Herniated Disk: Outcomes and Costs at Two and Four Years for Surgical and Non-Surgical Patients*

* Please Note:

“As Treated” Results for SPORT. Blue denotes surgical patients & yellow denotes non-surgical patients. Costs on bars reflect the estimated total direct costs plus indirect costs for spine care. QALY denotes “quality adjusted life years” associated with treatment. Costs in center of circle denote the incremental cost per QALY. Incremental cost-effectiveness ratio (ICER) is the cost per QALY (EQ-5D) gained for surgical treatment relative to non-operative care with Medicare surgery cost.

Herniated Disk Outcomes @ 2 Years

Herniated Disk Outcomes @ 4 Years

FIGURE 9

Spinal Stenosis: Outcomes and Costs at Two and Four Years for Surgical and Non-Surgical Patients*

Spinal Stenosis Outcomes @ 2 Years

Spinal Stenosis Outcomes @ 4 Years

* Please Note:

“As Treated” Results for SPORT. Blue denotes surgical patients & yellow denotes non-surgical patients. Costs on bars reflect the estimated total direct costs plus indirect costs for spine care. QALY denotes “quality adjusted life years” associated with treatment. Costs in center of circle denote the incremental cost per QALY. Incremental cost-effectiveness ratio (ICER) is the cost per QALY (EQ-5D) gained for surgical treatment relative to non-operative care with Medicare surgery cost.
MANAGING PRIVACY AND SECURITY
All patient-clinician electronic communications occur within a secure patient portal to ensure compliance with HIPAA security protocols. Whether the patient is contacted by email, letter or phone, the health survey access will only occur via a password protected sign-in for data collection and encrypted data transmission. If a patient is being offered the opportunity to participate in a research study, then informed consent will be obtained before access is granted to the health survey.

The health survey results are stored centrally in a data warehouse behind a secure firewall. A limited data set is made available to authorized users for aggregate analysis.

PATIENTS’ AND CLINICIANS’ VIEWS ON PATIENT-REPORTED MEASUREMENT SYSTEMS
Observations and surveys show that most patients have had favorable views on the Spine Center’s patient-reported measurement system. For example, Hvitfeldt and colleagues conducted a study on how patients and clinicians viewed the Spine Center’s patient-reported measurement system as well as the Swedish rheumatoid arthritis patient-reported measurement system discussed next as Case #2. The study focused on patients’ (n=44) and clinicians’ (n=13) perceptions of how the system worked and was based on questionnaires and interviews administered to patients and on interviews with clinicians. Overall results showed that over 80% of patients rated the system as “excellent to good” and one-third indicated that the patient-reported measurement system had led to positive changes in their visit (compared to other clinics that do not use patient-reported measurement systems). Some illustrative comments follow.

- “The visit became very helpful, thorough and informative.”
- “The visit went more quickly by asking all the questions beforehand, the
Clinicians reported that patient-reported measurement systems were extremely important for both follow-up and feedback and that, in their view, most patients found the system useful and positive. About half of the clinicians stated that the system saved time and about half believed it added time. Some illustrative comments follow.

- “Only a small percentage (of patients) disapprove of using the system. Mostly they understand we are all helped by it.”
- “Patients get more involved in their care – that helps the treatment.”
- “Without the patient-reported measurement system, we can’t give the patient feedback.”
- “The summary is very good to look at before you meet with a new patient.”
- “The health questionnaire results act like a channel for communication.”
- “This changes how health care is delivered.”
- “It is easier to talk about sensitive issues such as mental status.”
- “Though working with the system adds extra time, I understand the greater good of it.”

Although both patients and clinicians tended to have favorable opinions about the patient-reported measurement system, both groups also voiced concerns or expressed opportunities for improvement. Some of the most commonly mentioned concerns suggested that the survey was too long, some questions seemed repetitive, it may be hard for some people to complete the survey (older, vision impaired, low literacy), and the amount of time it takes to answer the survey (patients) or the amount of time it takes to complete a visit (clinicians).
Karolinska University Hospital and the Swedish Rheumatology Quality Register

CONTEXT AND SETTING
The Karolinska University hospital, located in Stockholm, Sweden, is the home of the Swedish Rheumatology Quality (SRQ) registry that aims to improve the quality and value of care for people suffering from arthritis and other rheumatic diseases. Health care in Sweden is organized by the 20 counties where it is tax funded. National supervision of care is led by the Ministry of Health. The SRQ registry started in 1995 using paper forms and began replacing paper forms with patient-reported web services in 2003. The SRQ registry is a longitudinal database that follows patient outcomes over time. Dr. Staffan Lindblad and Helena Hvitfeldt Forsberg lead the design and dissemination of the web-enabled SRQ registry using similar patient-reported methods that they first observed when visiting the Spine Center at Dartmouth-Hitchcock. The web-enabled SRQ registry makes use of real time, standardized data provided by patients, clinicians and diagnostic tests to improve the outcomes of care for individual patients, at the point of service as care is provided and in the patient’s home to support self-management, as well as for quality improvement and research. By 2012, 25 of the 64 clinics were using the web services option to generate patient-reported data reports to support care delivery in the flow of care and feedback reports for quality improvement and research. As of this writing, another 15 clinics are preparing to implement the patient-reported measurement systems.

The SRQ system supports the clinical microsystems that organize care for patients with rheumatic diseases. According to Lindblad, the process includes three fundamental and inter-related parts: patients and providers (the P2) and information/informatics (the I) in the P2I care system. The patients enter their data on joint pain and current health status using a secure SRQ website and this information is automatically analyzed and trended. The analysis is instantly provided to the patient for use on his or her own, as well as to the provider. The provider may enter or update the information on diagnoses, health status, treatments and test results on the same SRQ website. The SRQ registry also includes data provided by patients and providers and data from diagnostic tests, which are combined to produce feedback reports for use at four levels: the individual patients, the providers’ panel, the population of the clinical department, and national benchmarks.

DATA COLLECTION AND USES
In Figure 11 (page 24) the patient-reported measurement system process at a rheumatology clinic is illustrated by a simple diagram. A summary of the flow and uses of the data follows.

Feed Forward Patient Reports
Patients with rheumatic diseases complete a self-administered health survey before the visit to the provider. Each registration is performed on a touch screen computer in the waiting area and takes 10-15 minutes (see Figure 12, page 25). Through a secure patient Internet web portal, patients can register data prior to their meeting with their provider, from home or work. Patients enter data on general well-being, pain, swollen and/
or tender joints, how well they can perform daily activities, health related life quality (EQ-5D) and ability to work. Depending on the patient’s diagnosis, the health survey questions vary to reflect the specific condition of the patient. Data reported by the patient is compiled into a summary overview visualizing all previous visits compared to the data just registered (see Figures 13 and 14, page 25 and 26). At this point, data on treatment and medication is pending on the visit with the provider. The summary overview is printed for the patient to look at while waiting to see the provider.

**Feed Forward Clinician Reports**

At the time of the visit, the provider and patient review the information together and the provider registers additional data on prescribed treatments, medications, dosages and any adverse events. The provider only needs to enter data into the SRQ or the electronic health record as the two systems are linked and data is automatically exported from one system to the other. Earlier treatments, medications, and their effects are easily viewable in the clinical summary which functions as a decision support tool for patients and providers in deciding on the next treatment steps. An updated summary overview is printed for the patient to bring home.

**Return Visits and Follow Up**

For return visits to the Rheumatology clinic, the patient repeats the registration and data entry process before meeting with the provider. The SRQ provides multilevel feedback; at the patient level effects of treatment outcomes can be evaluated and each provider can analyze their respective patient group to prioritize work. At the clinic level, the patient panel progress can be followed along with medication trends. At a national level, benchmarking is made possible by comparison of data to the clinic or regional level as shown in Figure 15 (page 27). Examples of data presented are diagnosis, gender and age distribution, treatments and treatment combinations.
**Figure 12**

Patient Registering Data on Swollen and Tender Joints on a Touch Screen Computer in the Waiting Area

**Figure 13**

Summary Overview of a Rheumatology Patient
Data Trust and Warehousing
All rheumatology clinics own the data they provide to the SRQ registry. The 64 clinics feed data to the national database, but only the clinic itself can view its own results and compare its results to the national level. Researchers use data from the SRQ to explore and understand interactions of drugs, adverse events and treatment trends. All extraction of data requires ethical approval and is decided by the SRQ board for the local clinics that have contributed data. In cooperation with the pharmaceutical industry, data on medication use is provided to 6 different companies supplying biological treatments for rheumatic diseases as a DCDS (Data Content Display Service.)

Feedback-data Analysis for Program Improvement, Public Reporting and Research
The SRQ registry is used for multi-dimensional evaluation of medical, functional and patient satisfaction with treatment, which constitutes the basis of patient-centered improvement work and is integrated into everyday care practices. The results are available across organizational and professional borders for professionals, management, patients and the general public. The registry provides real-time feedback and is integrated with the major electronic health record system in Sweden.

There are two types of public annual reports from the SRQ registry that aim to help improve care for chronic patients by benchmarking treatment results, and also to highlight what has been accomplished and to identify improvement opportunities.

The Annual SRQ Report offers a summary on the efforts and outcomes during one year. The report contains accomplishments on different levels of care; from comparative data on treatments given and their outcomes to health care management of chronic patients. Data on treatments, drugs and patient outcomes are presented from different clinics throughout Sweden and also aggregated on regional and national levels.

The Open Comparisons from the Swedish Association of Local Authorities and Regions (SALAR) aims to stimulate comparisons and contribute to a greater openness concerning health care results and costs for the activities that are conducted by
municipalities and county councils. Every year SRQ registry provides data on patients and drug utilization to be benchmarked among the different rheumatology clinics within Sweden. These open comparisons are available to the public and online.

An important project that aims to improve chronic care is called Clinical Development Utilizing Registries (C.U.R.). C.U.R. builds on the SRQ registry effort, which has created prerequisites for radically improving health by supporting the complete chain of research linking clinical, translational and implementation research through registry data. The SRQ registry has further developed a platform for enhanced competitiveness through formal agreements with the life science industry. Several other specialties, such as neurology and pediatrics, have begun a similar development thanks to C.U.R.

C.U.R. is centered on the unique Swedish multitude of national quality registries with systematic data on care provided and health outcomes achieved for specific medical conditions. C.U.R. enables the registers to utilize their knowledge to enhance clinical research and care delivery by using the generic modules developed by C.U.R. to collect and analyze registry data on any clinical condition and intervention.

**FIGURE 15**

Disease Activity Score progressions (mean) for patients with early arthritis over time in the SRQ, from 1996-2011

The red line represents DAS at initial visit, the blue after 3 months, the green after 6 months, and the orange after a year and the purple line after two years.
SELECTED USES AND ILLUSTRATIVE REPORTS AND DATA DISPLAYS

Use of Systems to Promote Behavior Change

An essential element in all behavior change is feedback, which is learning about the consequences of actions taken. The SRQ registry delivers multi-level feedback to patients, providers and clinics. Through feedback on performance measures, each clinic has the opportunity to improve its work. Data put into the SRQ registry can be extracted at any time by managers and doctors at the clinic. These data concern prescribed drugs and combinations of drugs, diagnosis distribution, disease activity over time, and use of the patient-reported data. The challenge is to make follow up work systematic and continuous, and not just an annual activity. Reports like Open Comparisons benchmark each rheumatology clinic’s performance to a national level. The graph shown in Figure 16 (opposite page) shows changes in RA patients perceived global health, 4-12 months after the start of treatment with biological drugs, stated in percentage for two time periods. The publication of these data may induce some changes. Behavior change, at the level of patient-provider interaction, is focused on letting the patient be a participant in care and not only a recipient. Instant feedback on registered data through the touch screen makes patients aware of their health status and the summary overview acts as a tool for communication between patient and provider. With transparent data, providers can share information; and based on new data from the patient, focus on the important things right now.

C.U.R. Reports

C.U.R. is working with a number of clinical registries and databases and has developed 10 generic modules for different purposes. One of the modules focuses on the very important topic of the patient’s perspective and active participation. Patients want health care professionals to have access to current, structured information about their diseases at each contact, in a format that is easily understood by the patient. Within the C.U.R. project, new graphic depictions of disease progress and effects of medication have been created, as shown in Figure 14. These reports can be printed out during the visit, and they are perceived as very useful by both patients and their families and in meetings with other new health care providers. These reports show the entire registered disease course: the response to all treatments given, disease progression and treatment response. Improving everyday contact with patients helps to create a quality registry with complete and valid data that serve as prerequisite for all other functions.

Another crucial point that C.U.R. focused on is the need for health care to generate new knowledge about the prevention and treatment of disease. Patient contact offers a natural but underused opportunity to gain knowledge about causes as well as effects and side-effects of various therapies. Most ordinary diseases are caused by an interaction of genetics, lifestyle and environmental factors. Current research explains the interactions among environment, heredity and the emergence of diseases in new ways. By using the registries to study causes of diseases for a variety of individuals, the C.U.R. has, for example, demonstrated that smoking is a far more important cause of rheumatoid arthritis (RA) and multiple sclerosis (MS) than previously believed. Studies like this can be carried out using quality registries and may present new information on disease prevention at the population level as well as for high-risk families. Questionnaires for risk factors of cardiovascular disease are being included in the patient-reported measurement system, including smoking. The combination of quality registries and biological samples (mostly blood tests) saved in bio-banks.
allows matching of drug/patient information for maximum therapeutic effect. This combination enables personalized health rather than personalized medicine. This is of particular interest when several different (often expensive) drugs are available, as often occurs in rheumatology.

**SRQ Reports**
The SRQ registry is used by all rheumatology clinics in Sweden. All data are stored centrally and used to generate Annual Reports on treatments and patient outcomes (Figure 15, page 27). To ensure that data is of good quality, educational courses are held at the different clinics for the clinicians to learn how to register and extract data from the SRQ registry. Each course is half a day and teachers travel to the clinic. The courses are free, and are customized for each clinic around three general themes. Theme one educates users on how patients and doctors can use the registry in daily

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**Graph from the Swedish Public Performance Reports on Health Care and Social Services from 2010**

The graph shows changes in RA patients perceived global health, 4-12 months after treatment start with biological drugs, in percentage. The orange bars are based on data from 2008-2010. The light grey bars represent previous values.
care (to input data and view real-time summaries.) Theme two deals with how the continuously updated dynamic diagrams can be analyzed and used for the clinic’s improvement. Theme three revolves around the search engine of the registry, which enables users to retrieve various data points.

**Comparative Effectiveness Research**

The C.U.R. project is intended to describe and develop Swedish quality registries as a foundation for enhancing health care quality, clinical research and collaboration between research and industry. The report concludes that utilization of quality registries will allow Sweden to develop health care at local and national levels while improving research and industry collaboration from an international perspective.

**MANAGING PRIVACY AND SECURITY**

All data and communications within the SRQ registry are regulated according to the protocols of the Swedish Data Inspection Board. Data within the SRQ are stored locally and used for patient-reported measurement and decision support, local follow-up and data quality work on an individual patient level. Data are transferred to a central database, stored nationally and organized at the individual patient level. In this database, all patients have a unique pseudonymous number. Thus, all group data analysis and presentations are based on de-identified patients, in accordance with the Data Inspection Board, to assure integrity and safety.

**PATIENTS’ AND CLINICIANS’ VIEWS ON PATIENT-REPORTED MEASUREMENT SYSTEMS**

In a comparative study on the two patient-reported data systems, the one used at the Dartmouth-Hitchcock Spine Center and for rheumatology patients, the work sought to understand the patients’ and clinicians’ perceptions of the system using the indicators of acceptance, use and utility. The study methods and main results have been mentioned previously in the Spine Center case.

Despite being adapted and used in different contexts, essential properties that induced successful patient participation and provider support were found to be universal in the patient-reported measurement systems. Interviews with both patients and providers indicated that the patient overview and displaying structured data previous to the clinical encounter are favorable. These essential properties enabled patient involvement through engagement, education and communication with the provider, who appreciated them as time-saving for managing data and as a decision support for next steps in the patient’s care.
The Group Health Case Study of an Electronic Health Risk Assessment Tool

CONTEXT AND SETTING
This case study describes the development and use of an electronic Health Risk Assessment (e-HRA) targeted at adults and integrated with an electronic health record at Group Health Cooperative, a large health care system and health plan in the State of Washington. The overall purpose of the e-HRA is to provide actionable advice to patients and their care teams based on health risk and history information entered by patients into their electronic health record. Aggregate data are also used by purchasers and the health plan for population health improvement planning.

Founded in 1946, Group Health Cooperative is a mixed-model integrated health care system that serves approximately 675,000 patients in the State of Washington. Group Health offers public and commercial insurance products to large and small employers, individuals and families, Medicare enrollees (the U.S. federal plan covering seniors and the disabled), Medicaid enrollees (the state plan covering the poor), Basic Health (a State of Washington public-option health plan), and the State Children’s Health Insurance Plan. Most patients receive their care in 25 Group Health owned-and-operated primary care clinics that have onsite pharmacies, laboratories, and radiology suites. The clinics are supported by 10 Group Health specialty/behavioral health units, 6 urgent care/emergency departments, and 7 acute care hospitals, (1 owned and operated and 6 contracted hospitals.) The Group Health Physicians medical group, which contracts exclusively with Group Health to provide care to its members, employs approximately 990 physicians in 75 specialties and subspecialties.

Starting in 2002, Group Health implemented a system-wide advanced electronic health record, EpicCare, that includes ambulatory documentation for primary care clinicians, specialists, nurses and other clinical staff; prescription order entry and dispensing records; laboratory results, radiology images and reports; pathology results, virtual consultations, mental health care records; and services provided by a variety of ancillary health personnel (such as physical therapy, occupational therapy, social work, telephone consulting nurse, and home care). In addition to making care delivery virtually paperless with a patient’s complete record available at the point of care, members can access parts of their own record through a secure web portal (MyGroupHealth). Members are able to review results, read visit summaries, make appointments, fill prescriptions, review health benefits, and get vetted health information. In addition, Group Health actively promotes the use of secure electronic messaging between patients and their care providers as a substitute to in-person visits or telephone calls. Electronic messaging has been a key component of Group Health’s implementation of the patient-centered medical home (PCMH), “virtual visits” now represent approximately 65 percent of all clinical encounters in primary care.

In 2006, Group Health developed the “Health Profile,” an interactive online electronic health risk assessment (e-HRA) that collects self-reported risk factor information from adult members, integrates it with data in their electronic health records, and produces personalized health improvement recommendations on a wide range of clinical topics.
The Health Profile is a feature of MyGroupHealth and allows patients to receive personalized health information and communicate health risk and other information to their clinical teams in preparation for a preventive care visit. The recommendations produced by the Health Profile align with Group Health’s clinical practice guidelines. A detailed summary report is also available in the electronic health record for care teams to review recommendations and health history information.

Development of the electronic health record-enabled e-HRA at Group Health was prompted by the convergence of a variety of trends and evidence streams. In the U.S., large employers are increasingly embracing wellness programs in the hope of stemming the rate of growth of health care expenditures, improving workforce productivity, and increasing their profitability. Employers are looking for programs to motivate employees to engage in sustained behavior change and chronic illness self-management. The entry point of most employee wellness programs is an e-HRA that combines a questionnaire to identify an employee’s health related risks, tailored feedback to motivate positive behavior change, and targeted referrals to wellness programs and other preventive services. Increasing evidence suggests that health risk assessments can be effective in prompting the uptake of prevention and health promotion activities when used in the context of comprehensive worksite health promotion programs.

The health services research evidence-base also suggests that, in addition to employee wellness programs, physicians and health care providers have an important role in prompting patients to change risky health behaviors, including tobacco use, harmful drinking, risky sexual practices, and habits leading to overweight/obesity. There is also evidence that physician advice, combined with wellness programs and appropriate pharmacotherapy, can complement tobacco cessation. From Group Health’s perspective, the ability to link employee strategies with physician strategies to promote prevention and chronic illness care was a main impetus for development of the e-HRA.

The implementation of a web-based advanced electronic health record with shared features between patients and their care teams, created the technical infrastructure to develop an integrated e-HRA that could collect information directly from members and feed recommendations immediately back to them through the web portal and to their clinical teams through the electronic health record. The technical infrastructure available at Group Health is not unique with growing penetration of electronic health records, and electronic questionnaire interfaces in the U.S. and worldwide. Several medical history intake systems are being marketed with electronic health record integration. Evidence is also accumulating that structured electronic questionnaires in the clinical setting improve the availability and accuracy of medical record information and the recognition of previously unidentified problems.

**DATA COLLECTION AND USES**

**Data Collection**

The e-HRA was designed as a 15-20 minute survey delivered through the patient’s electronic health record portal. Figure 17 is an example of a patient’s “home page” with the Health Profile as one listed activity. The Health Profile targets adults and seniors of all ages and is available at any time. Patients can complete it as often as they wish. Group Health advertises it heavily in health fairs, on the web, and in its
member magazine, “Northwest Health”. Clinical practices are guided to prompt their care teams to complete the questionnaire as part of new member on-boarding and in preparation for a prevention visit. Group Health also partners with employers to incent Health Profile completion as part of its employee wellness programs. Incentives take many forms, including both financial and non-financial incentives. There is strong evidence to suggest that financial incentives are critical to promote completion and uptake of health risk assessments.\textsuperscript{29, 30}

The questionnaire topics include:

- \textit{Personal information} (including demographics, living circumstances, social support, advance directives, and hobbies and interests)
- \textit{Past medical and surgical history}
- \textit{Medication use} (prescription and non prescription)
- \textit{Health behaviors} (obesity/overweight, nutrition, physical activity, tobacco, alcohol, stress, substance abuse, risky sexual behaviors, and contraception)
- \textit{Chronic disease control} (asthma, heart failure, depression, diabetes, hypertension and diabetes)
- \textit{Disease risk} (colorectal cancer, lung cancer, breast cancer, diabetes, and cardiovascular disease)
- **Clinical preventive services**, including cancer screenings (colorectal, cervical, breast and prostate cancers), other screenings (depression, cholesterol, Chlamydia, osteoporosis, and abdominal aortic aneurysm), immunization (pneumococcal, tetanus, influenza, and herpes zoster), preventive medications (aspirin, ACE inhibitors, statins, calcium, vitamin D, and folic acid)
- **Medication management issues**
- **Health status** (functional health status, health-related quality of life, hearing and eyesight problems)
- **Occupation and workplace productivity** (absenteeism and presenteeism)

The questionnaire contains extensive branching logic and “behind the scene” automated algorithms to determine health care needs and calculate risks. It also has two-way data integration with the electronic health record where pertinent demographic, biometric, and laboratory details are extracted and presented to the patient for confirmation (such as last blood pressure and cholesterol test results). This data integration obviates the need for patients to remember or retrieve this information from other sources. The Health Profile data are immediately migrated to the electronic health record for care teams in the form of reports and structured data. Automated algorithms are also used to trigger messages to a member’s health care team if a poorly controlled chronic illness is detected. Reports are archived on the electronic health record and the web portal to provide the ability to track changes over time. See Figure 18 for an example of the e-HRA questions.

**FIGURE 18**

![Example of the e-HRA Questions](image-url)
Data Uses
Group Health’s e-HRA has multiple purposes directed at four audiences: patients, care teams, health care purchasers, and health care leaders.

Patients
The primary audience for the Health Profile is patients. The Health Profile is designed to directly promote patient engagement and activation in preventive care activities and chronic illness care by providing immediately actionable information upon questionnaire completion. The health risk assessment can be used independently by patients or it can be used in the context of their health care, such as when they newly join the physician’s panel or in preparation for a preventive care visit. The Health Profile is designed to systematically identify health risks and provide individuals with evidence-based recommendations for primary, secondary and tertiary prevention. Because patients have multiple risks and health care needs, the Health Profile also assists them with prioritizing these prevention activities. The Health Profile is based on Prochaska’s theory of behavior change.31 Questions are delivered on the patient’s readiness-to-change risky behaviors (or adopt health promoting ones) from which behaviorally tailored messages are then delivered. Because of the evidence that health risk assessments are only effective if they are linked with health promotion programs,22 the Health Profile also links patients with available resources or services at Group Health or in the community.

As opposed to typical health risk assessments, the Health Profile also enables patients to enter other personal health information directly into their medical record for use by their clinical teams. This information includes demographics, medical history, self-reported health, functional health status, and social circumstances. This feature is designed to promote strong patient-clinician relationships based on mutual knowledge and understanding, a cornerstone of contemporary primary care.

Physicians & Care Teams
The Health Profile collects information useful to physicians and care teams to guide care delivery and enhance relationships. The Health Profile functions as a decision support tool to systematically identify prevention and chronic-care needs and then immediately delivers actionable information (such as screening needs) to care teams that make clinical practice guidelines “come to life.” Topics included preventive care screenings, chronic illness care, medication monitoring, behavioral counseling, immunization, and chemoprophylaxis. In addition to identifying needs, the Health Profile provides future disease risk estimates using evidence-based risk equations such as the Framingham Index for cardiovascular disease risk.32 The Health Profile doubles as a health history taking tool and expedites the systematic identification of a broad range of unmet needs. The Health Profile can reduce the history taking burden that consumes substantial time during a clinical encounter by delivering the information in the electronic health record ahead of the visit. The Health Profile also delivers structured data, which may not be systematically collected in everyday practice, including health-related quality of life and functional health status. The Health Profile also inquires about sensitive
issues such as harmful alcohol use, substance abuse, and risky sexual practices, which care teams may find difficult to ask face-to-face. Finally, the Health Profile identifies issues that need urgent attention (for example, poorly controlled congestive heart failure) and because of the electronic health record integration, is able to give immediate prompts to clinicians and the care teams.

**Employer & Government Health Care Purchasers**

In addition to providing individual level information to patients directly and care teams, the Health Profile delivers population-based estimates of disease risk, health status, and health care delivery gaps to health care purchasers. This information assists employers in the design of their wellness programs, prevention benefits and workplace redesign, (such as providing café and vending machine healthy food options). It also serves a performance assessment role, as it allows employers to see the quality of service delivery provided by Group Health providers; they can then use these data and similar information from other provider groups or health plans in their purchasing decisions. Finally, the Health Profile provides key population-based information on the health-related productivity of their workforce (such as absenteeism and presenteeism).

**Health Care Leaders & Managers**

The final audience for the Health Profile is Group Health leaders and managers. By providing population-based estimates on health care needs and service gaps, the e-HRA can assist with fine-tuning resource allocation across populations, service areas and clinics. It can also assist with stratifying the populations for outreach by clinicians, care management programs, and wellness programs. Finally, it can document the variability in the provision of prevention and chronic illness care across clinical populations to enable quality improvement activities.

**REPORTS AND DATA DISPLAYS**

**Feed Forward Patient Summary Reports**

Highly customized reports are delivered to patients via the web portal immediately after they complete the questionnaire. (See Figure 19 on page 37 for an example of the report.) The content of the report is tailored based upon risk factors, health history, and readiness to change. An “at-a-glance” summary table is prominently displayed using red-yellow-green color bars to quickly orient patients to the areas where preventive care services are recommended, health risks are elevated, or risky health behaviors are identified. The report also discusses when and how to seek care from their care team; prompts are given to patients to make needed appointments. Links are also made (often with embedded hyperlinks) to other information sources, wellness programs, and health coaches, depending on the needs identified. Past reports are securely archived on the web to enable patients to track their progress over time.

**Feed Forward Provider Summary Reports and Electronic Health Record Integration**

For physicians and care team members, a variety of information is exported back to the electronic health record in the form of structured data, free text, and summary reports in easy-to-find locations (Figure 20; see page 38). A customized primary care team summary report is delivered immediately after the patient completes a
questionnaire. (See Figure 19 for an example.) The primary care team report is similar to the patient report in content, but care gaps and other information are summarized in a manner familiar to physicians. The report becomes its own electronic health record “encounter” that tracks pertinent positives and negatives, and suggests clinical actions. Selected data points (for example past medical history, family history) are migrated directly to electronic health record fields. Where urgent concerns are identified (such as poorly controlled chronic illnesses), the Health Profile triggers an in-basket message to alert the clinical team or health plan care management team.

Employer/Purchaser Reports
Summary information is aggregated by employer or purchaser on a regular basis for use in health surveillance and performance tracking. (No individual data on employees is shared with employers). Aggregate patient-reported information is provided to employers/purchasers on response rates, demographics, lifestyle risks, chronic disease control, preventive service use (such as mammography), health-related quality of life, and workplace productivity. Information is mapped against comparative populations, when available. Small cell sizes are suppressed to protect confidentiality. Health Profile data are integrated with other standardized reports on utilization and quality.

MANAGING PRIVACY, SECURITY AND INTRA-OPERABILITY
The Health Profile operates with an established patient portal to ensure compliance with HIPAA security protocols. Health Profile access is allowed via a password-protected single sign-on to MyGroupHealth for data collection and transmission. To
support interoperability, the e-HRA and the Epic electronic health record data are passed through a secure XML interface. This transmission contains all discrete e-HRA data elements and has clear clinical designators. Epic translates the e-HRA data into standard HL7 v2.x messages. HL7’s Version 2.x messaging provides standards for interoperability that improve care delivery, optimize workflow and reduce ambiguity.
In this section we discuss key aspects of patient-reported measurement systems by summarizing lessons learned, discussing their utility, challenges, costs, design and implementation principles, and identifying emerging opportunities.

LESSONS LEARNED: HIGH LEVEL SUMMARY AND GRANULAR LIST

We begin our discussion of lessons learned with a high level summary and then provide more granular observations.

High Level Summary

The three case studies based in three distant locations—Northern New England, the Pacific Northwest and Sweden—provide a rich tapestry for learning about the potential power of harnessing and leveraging patient-reported information in the provision of clinical care and population care management.

The Dartmouth-Hitchcock Spine Center and Swedish rheumatoid arthritis case studies illustrate how patient-reported measurement systems can be developed and deployed to improve the care of people with specific, serious medical problems by tracking their evolving health outcomes. The systems also demonstrate the uses of these databases for clinical trials and epidemiological research, as well as for public reporting to help consumers and payers assess the value of the services provided. In contrast, the Group Health system shows how patient-reported information can be used to educate and activate an unselected clinical population by using instant feedback to the patient about health risks, care gaps and chronic care needs. This enables patients and primary care teams to be prepared and proactive in managing the health of individuals and clinical populations. It also offers employers an advanced system for assessing and promoting employee health based on evidence-based prevention and chronic care management best practices.

All three patient-reported measurement systems have endeavored to make the data collection and feedback process user-friendly for patients and efficient for busy frontline clinical teams. Using patient-reported data to populate conventional (or expanded) health histories could be more efficient and easier to update over time and therefore have the potential to save the clinician time in gathering critical information. All three cases aim to use the patient-reported data to engage the patients about their health care and behaviors, to catalyze personal health promotion and self-management and, at the same time, improve the doctor-patient relationship by spotlighting health data (on preventive needs, functional health status, or other health-related concern) that are important to the patient but can be easily overlooked. By the same token, all three cases illustrate the challenges inherent in any attempt to adapt health information technologies to fit unique clinical care routines.

All three organizations have moved “upstream.” They encourage patients, when possible, to enter their data from their homes using a secure web service and thereby move the data collection process away from the office. And all three have attempted to use state-of-the-art policies and processes to protect privacy, confidentiality and security of their patient-specific databases. Finally, all three organizations are
continuously trying to update their technology and to move toward expanded data exchanges and interoperability (between patient-reported data and clinician-reported data repositories) and the systems that support their collection, analysis and use.

**Lessons Learned: A More Granular Listing**
In addition to some of the more sweeping themes mentioned above, the case studies have generated a rather long list of particular lessons about things that should be promoted and avoided to increase the utility of these patient-centered patient-reported measurement systems. Table 1 summarizes these more granular lessons and observations that fall into the following categories: contents, adoption, electronic health record integration, delivery options, privacy and security, flexibility and modifiability.

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**TABLE 1**

**Specific Lessons Learned and Observations Made**

<table>
<thead>
<tr>
<th>CONTENT</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>• An ideal health assessment (HA) provides patients with a comprehensive report that summarizes their health status, their care needs and gaps in care.</td>
<td></td>
</tr>
<tr>
<td>• It is easy to overburden respondents: use principles to prevent this.</td>
<td></td>
</tr>
<tr>
<td>• Items should have a clear purpose and be user friendly, salient to patients and care teams, and actionable.</td>
<td></td>
</tr>
<tr>
<td>• Items should be brief, valid, reliable and sensitive to change.</td>
<td></td>
</tr>
<tr>
<td>• Items should be useful in clinical settings and facilitate delivery of evidence-based care.</td>
<td></td>
</tr>
<tr>
<td>• Items should not be included if there is insufficient evidence to support clinical or other interventions.</td>
<td></td>
</tr>
<tr>
<td>• The effectiveness of interventions varies based on patient-specific factors (age, sex, illness burden, patient activation, socio-economic status); therefore, it is often wise to tailor items to the respondent by using branching algorithms and/or computerized adaptive testing to deliver the appropriate questions and messages. This enables targeting issues relevant to each patient, reduces respondent burden and omits questions and feedback that are not relevant.</td>
<td></td>
</tr>
<tr>
<td>• Health literacy varies; therefore it is best to use plain language and to organize information so that the most important points are prominent. Supplemental materials (pictures and symbols) can aid understanding.</td>
<td></td>
</tr>
<tr>
<td>• Questions and reports should be tailored as much as possible to reflect the age, cultural, ethnic and racial diversity, health conditions and health status of the population(s) of interest.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>ADOPTION</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>• Overall usefulness, at both the individual and population level, depends on achieving high adoption, completion and follow-up rates, promoting the ability to track changes in health status over time.</td>
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<tr>
<td>• Low response rates compromise the utility of HAs, particularly for those who are at high risk and may be less likely to participate.</td>
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<tr>
<td>• Financial incentives, particularly cost sharing differentials, have promoted HA participation at Group Health.</td>
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<tr>
<td>• Setting the expectation that patient-reported data is needed as a precondition for a clinic visit has promoted participation at Dartmouth-Hitchcock and Karolinska.</td>
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</tr>
<tr>
<td>• Collaboration with key stakeholders, (such as employers, purchasers, researchers, patient advocates) can enhance adoption and use.</td>
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</tbody>
</table>
EHR INTEGRATION

- An ideal HA provides patients with a comprehensive report that summarizes their health status (risk, disease and function) and identifies all their care needs and gaps in care.
- Clinical teams need access to this information and recommendations, displayed in a brief format with recommendations prioritized.
- Beware of information and multiple “click” overload.
- Differentiate patient- vs. provider-entered information.
- Build summary reports in a way that matches pre-visit, during-visit and post-visit workflows and activities.
- Build the capability to correct information the patient mistakenly enters, before it becomes permanent in their record.
- Consider having an option for patients to not have information shared with their care team(s).
- Integrate direct-to-patient decision support with other EHR decision support or information tools.
- Providers will want the capability to learn why patients triggered certain recommendations.
- When urgent care issues are identified, information should be relayed directly to care team/s; workflows should be created to respond reliably and quickly.
- Very time critical items (such as, suicidality) should not be asked unless robust and consistent processes have been developed to respond reliably and quickly.

DELIVERY OPTIONS

- Electronic is gold standard but may need other delivery mechanisms (for example, paper, telephone use, interactive voice response (IVR).
- Trade offs in the scope and ability to tailor.
- In-clinic computer kiosks and touch pad computers may be used but pose security risks.
- Modular development of survey content is ideal to enable customized administration of topics that match patient/s needs and conditions.
- Feed forward information (for example, patient’s prior responses, EHR data) are vital to promote utility.
- Information icons can be helpful to improve understanding.
- Use state-of-the-art web design techniques, data display options, and usability testing.

PRIVACY & SECURITY

- Comply with all relevant federal policies and laws (such as HIPAA).
- Provide patient with choice to opt out of providing sensitive data.
- Provide patient with choice to block transfer of data to health care team(s).
- Provide patient with ability to block use of data for research purposes.
- Obtain IRB (or equivalent entity) approval of entire item set for use with patients.
- Suppress small numbers in population reports to avoid identification.

FLEXIBILITY & MODIFIABILITY

- Because health care recommendations change over time, be prepared to make rapid changes to e-questions, messages and algorithms.
- Because accreditation standards and reimbursement policies are evolving, build in the flexibility to respond rapidly.
- Build process to respond quickly to programming or content errors.
UTILITY AND FEASIBILITY OF PATIENT-REPORTED MEASUREMENT SYSTEMS

All three patient-reported measurement systems – Dartmouth-Hitchcock, Karolinska and Group Health – use their data to generate multiple outputs such as:

- patient-specific summary reports to activate patients
- data for clinicians to use to develop or revise the plan of care that best matches the patient’s needs and preferences
- data to trigger referrals and to identify gaps in care received for needed preventive services
- aggregated clinical population health status reports to evaluate and improve care
- health outcomes and system performance reports to share with the public, and
- data sets for retrospective and prospective research

Patients and clinicians provide anecdotal data suggesting that patient-reported measurement systems can enhance patient engagement, and understanding about disease and treatment, make health care more patient-centered, more outcomes-based, and foster better patient-clinician relationships. Finally, the utility of the patient-reported data can be leveraged and multiplied by combining it with information from other sources (such as clinician reports, diagnosis data, biometrics, laboratory tests, medication lists, and claims data) to measure the outcomes and costs of care for discrete clinical populations and thereby promote accountability by health systems to measure the impact of their care on health outcomes and costs.

The feasibility and scalability of patient-reported data systems have been well established.

- The Dartmouth-Hitchcock Spine Center has used its patient-reported measurement system for over a decade. The model was adopted for use in the SPORT trial, funded by NIH and conducted in 13 medical centers spread the country. The Spine Center patient-reported measurement system has been adapted for 18 different clinical programs at Dartmouth-Hitchcock (over 70,000 patients have completed over 200,000 questionnaires). Dynamic Clinical Systems, an enterprise that helped develop the Spine Center patient-reported measurement system, now serves clinical programs in more than 25 different health systems across the United States.

- The national Sweden Rheumatoid Quality registry (SRQ), based at the Karolinska University Hospital, began converting its paper-based approach to a patient-centered, patient-reported measurement system in 2003 and by 2012, 25 of the 64 participating clinics were using the patient-reported, web-enabled option. They are now developing innovative approaches, involving simulation and action-oriented education, to make the process of adopting the web-enabled patient-reported measurement system easier for individual clinics to accomplish. And, the SRQ has become a novel model for operating clinical registries that is being endorsed for use throughout Sweden to improve care as well as to improve the research database needed to advance biomedical science.
• Group Health Cooperative made a strategic decision to leverage its large investment in an enterprise-wide electronic health record by incorporating patient-reported data and embedding it into its electronic health information environment through a patient-reported measurement system. The novel patient-reported measurement system that it has developed expands the capacity of its 25 primary care centers (the backbone of its delivery system) to prevent illness as well as to manage chronic disease in a more cost-effective manner. At the same time, the Group Health patient-reported measurement system aims to work as an advanced, evidence-based and behaviorally sophisticated health risk assessment system to help employers improve their employees’ health status, boost workforce productivity, and help reduce health care costs by making better use of preventive services and chronic disease self-management.

Furthermore, many other innovators and progressive health systems have developed patient-reported measurement systems that make extensive use of patient-reported data to serve hundreds of thousands of patients. Examples include, HowsYourHealth, developed by John H. Wasson, M.D.; Microsoft’s Health Vault; Dossia’s personal health record; and advanced use of the Epic patient portal (called MyChart) by lead users such as Group Health Cooperative and Dartmouth-Hitchcock.

USING PATIENT-REPORTED INFORMATION SYSTEMS: HAZARDS AND CHALLENGES

While this report has, for the most part, emphasized the benefits of using patient-reported information systems to improve care and contribute to research, there are some potential hazards and daunting challenges that must be recognized and managed. These hazards and challenges include:

• Not all patients will be willing or able to provide information about their health and their behaviors, and clinicians will need to respect this decision and collect this information orally or by other means, if possible.

• Some patients’ health status trends will show that their health status is getting worse, staying at a relatively low level, or that their risk of future health problems is high even if they are engaged in self-management and/or even receiving state-of-the-art care. It is important for clinicians to place the patient-reported measurement system results within the context of the patient’s current clinical state, prognosis, attitudes and preferences.

• Some health systems and some clinicians may not know what to do with the results. If, for example, patients are identified with significant care needs, such as severe depression requiring treatment, decision support resources may be required, including clinical practice guidelines and care protocols, to guide care in these circumstances.

As noted below, we believe that patients and practitioners benefit from having some orientation on the best ways to make the best use of the patient-reported data and to emphasize that patient-reported data, like
diagnostic test results, do not speak for themselves; rather they need to be verified, interpreted and used intelligently to guide care planning and assessment that best fits the patient’s needs and preferences.

- As with other innovations in health care, there will need to be a start-up period during which this new stream of data is inserted into the flow of care and patients and clinicians learn how to work together to make best use of this new information. This start-up period can be challenging as some clinicians and patients may be resistant to change and administrators may underestimate how much effort is required to make this type of change initiative successful.

**COSTS OF STARTING AND MAINTAINING PATIENT-REPORTED MEASUREMENT INFORMATION SYSTEMS**

This section discusses both costs and practical issues related to using patient-reported measurement systems.

1. **Initial Start-up**

A pilot test may be initiated by perhaps a single clinician or practice site within an organization. The test would “borrow” existing resources and would implement a small scale test with a limited number of patients. In being able to adapt the system to the context, the pilot site would identify issues that arise in actual practices and indicate opportunities for improvement. Achieving proof that “We can really do it,” the pilot site builds support within the organization for integrating patient-reported data into routine care delivery and ultimately serves to define the requirements for a later test site.

A site would determine what patient-reported outcomes, such as pain level or physical activity, could be used immediately during a visit to improve care delivery. The pilot could use a small number of questions from public domain surveys (such as pain level or a standardized physical activity questionnaire), create a simple paper survey tool, train a willing staff member to distribute and collect the instrument from the patient, compile the results from the paper survey and provide a summary to the clinician. A facilitation process, to debrief and reflect on this initial test, may require a borrowed resource, but will yield important information for the organization’s journey. Our context for this initial start-up is dependent upon a positive attitude from management, coupled with a champion who can run the project and inspire others.

2. **Data Collection – Web-based Services, EHR Integration**

When an organization commits to capturing self-reported outcomes data from many patients, across multiple clinicians, over extended time frames, an electronic technology platform is needed to enable a higher level of efficiency to capture these data. For many disease specific conditions, there are health surveys readily available. The cost of an Internet service can be low, electronic messaging for survey tool deployment is relatively simple, and there are available means to secure record-level patient data in compliance with patient data privacy and security protocols. This enables a two-way exchange of information with the patient and the clinic and is the approach that has been adopted in Sweden for the SRQ.

Enabling the connection between the Internet survey system to any commercially available electronic health records (EHR) is often costly because there is not an
industry standard for integrating outside data sources into the EHR, and it is often designed to be a proprietary feature. While this integration can also be quite time consuming, it supports an essential compliance concern in avoiding double registrations of data, thereby minimizing this potential project barrier. Depending on the vendor product and the challenge to program a data transfer interface, this development cost may be significant, perhaps as much as $50,000 of internal costs, when done by the organization’s IT programmer staff.

Another important but unavoidable cost of data collection is the effort put in by the patient. This time commitment from the patient in advance of a visit didn’t exist before the patient-reported measurement system was adopted. On the other hand, this system shifts some tasks away from the clinician, allowing a more informed, direct focus on the patient. The system also systematically records the patient voice to be used for care planning and shared decision making. Patients report that they have more time with the clinician with the patient-reported measurement system and a better quality visit that is more suited to their particular needs and preferences. Enabling immediate feedback, the learning experience for the patient is essential and provides concrete and perceptible benefits that balance against the patient effort.

During implementation, performing user evaluations with both patients and clinicians allows further adaptation of the system. As the system is deployed more broadly, additional development costs will depend somewhat on the disease process and clinical situation (acute or elective) that will drive the complexity of the tool (number of questions, frequency of responses).

3. Clinical Staff Resources
There will need to be time invested in team training using standardized training materials and with availability of an identified contact support person. Time away from the clinical setting or a period of slower productivity may be monetized and tracked. With an initial learning phase for all team members, simulation techniques may be effective to minimize the cost and maximize the efficiency of learning a new way to care for patients. Courses focused on registration and system data extraction can be brought to clinical sites to minimize the time required by clinicians.

It is important to examine and intelligently redesign established workflows to adopt the patient-reported measurement system into routine processes of care. Although the implementation phase will likely consume extra time, the final goal is to make better use of available time at clinician visits by having an enhanced assessment of the patient’s current and changing health outcomes. Many supporting members of the clinical team can assist with the deployment of the patient-reported measurement system for the majority of patients. In some cases, clinicians may only be consulted with aberrant results.

4. Infrastructure
The Group Health Research Institute invested approximately $1 million to start up their electronic health risk assessment system, which was modest compared to the ongoing maintenance and training expense. From the outset, it has been a challenge to integrate the patient-reported data with the electronic health record. Ongoing expenses have been substantial and include software maintenance, keeping the content up to date, training the reception and office flow staff, and training the clinical support team to monitor the completion of the survey so that the lack of the survey doesn’t disrupt the appointment.
The Medical Management Centre at the Karolinska Institute incurred less cost for the development and implementation of their patient-reported measurement system. Their greatest costs were in making the connections to the EHR and in initial system development.

Health providers may want to dedicate an existing staff person (or a new hire) to monitor the completion of the surveys and reach out to patients to request that they complete the survey before arriving. This staff person can provide IT support, or simple remedies that make the system workable if the patient is having difficulty with the software/hardware setup from their home or when the patient needs assistance to use the system. If patients wait until they arrive at the clinic to complete the survey, there may need to be an investment in computer kiosks or tablets in the waiting room. It is less efficient to have patients complete the survey when they arrive for an appointment both with respect to staff time and hardware.

**DESIGN AND IMPLEMENTATION PRINCIPLES**

The patient-reported measurement systems that have been featured in the case studies were designed, implemented and improved over time by invoking a set of guiding principles. These are listed below.

1. Design the patient-reported data system to
   - make it easier for frontline clinicians and support staff to do their jobs well
   - make it easier for patients and families to be engaged in care planning, shared decision making and self-management
   - generate actionable data and reports to meet the needs of other key stakeholders such as the larger health system, payers, employers, accreditors, collaborative improvement networks and research collaboratories (collaborative laboratories)
   - alert care teams about which assessments require timely outreach and intervention

2. Co-design the data displays and information content with end-users to meet their needs
   - consider using graphical, comparative, and longitudinal displays for communicating results
   - consider providing the patient with immediate guidance and information to promote personal health and evidence-based self-management, with opportunities for direct engagement to reduce risk

3. Determine what other data sources (such as diagnostic tests, clinician reports, claims data) will need to be tapped to enhance the value of the patient-reported data to end users
   - consider combining patient-reported data with other data streams to create measures of quality, health outcomes and costs of care

4. Embed data capture and data displays in the flow of care so that the best information is always in the right place at the right time to support optimal care for patients as their health status and needs change
   - embed validated patient-reported health status measures (risk status, disease status, functional status) in the question sets that patients complete as well as demographic and context questions
• consider using multiple methods to collect data (computers, touchpads, telephone interactive voice response and smart phones)

5. Educate patients, families, clinicians and support staff on the purpose of the patient-reported measurement system and how it can be used to benefit all parties
• consider using role-playing, simulation and location-specific flow charts to integrate the patient-reported data into the health care team’s roles and clinical processes

6. Improve the patient-reported measurement system over time by working with patients, families, consumers, clinicians, support staff, employers and other stakeholders to identify improvement opportunities and to discover new uses
• consider identifying lead users to determine what they are doing and what they want and need to do with the patient-reported data to improve their organization’s performance

7. Redesign the clinic workflow to incorporate patient-reported data collection and displays
• all points of contact should encourage patients to complete the patient-reported survey, starting with the scheduler when the appointment is made
• the health survey completion should be considered its own appointment, not unlike a lab test, that needs to be completed prior to the clinician appointment

8. Safeguard the data of such systems and require security practices, recognizing the potential sensitivity of self-reported data
• consideration of these principles in designing and implementing patient-reported data can lead to broader dissemination and more effective use

EMERGING OPPORTUNITIES
The case studies from Dartmouth-Hitchcock, Karolinska and Group Health highlight some of the best uses of patient-reported data in today’s health system; however, there are some innovative and possibly “game changing” developments that may transform health care delivery models and health care payment systems. Before concluding, we briefly touch on some novel forces that will make use of patient-reported data.

Tele-health
There is a massive trend toward home-based care that aims to provide sophisticated and less costly care to people with chronic conditions and palliative care needs in their own homes by leveraging tele-health technologies. Tele-health can use patient-derived biometric data (such as pulse oximetry, blood pressure, weight and blood sugar) as well as patient-reported data (such as signs, symptoms, and functional markers) to provide remote, real-time monitoring of the health state of individual patients. These patients are at home but under systematic surveillance by clinicians, who are connected with the patient through virtual modes of communication. For example, health status of elders in residence communities can be monitored passively to detect changes in physical and sociability levels. Also, some moderately to extremely ill patients can be monitored 24-7 remotely by qualified health professionals at lower cost and at greater convenience for patients and families.
Value-based Purchasing
There is a major shift in health care provider reimbursement toward paying providers for the value of care that is delivered instead of the volume of services provided. The movement toward accountable care systems, bundled payments for illness episodes, and medical homes all call for new payment schemes that aim to reward better measured health outcomes and lower costs per patient served. As noted above, some of the most important patient-centered data on health outcomes and health care experiences should be based on patient-reported data. These data can best be captured using data feed mechanisms such as those illustrated in the case studies.36; 37; 38

Employer and Consumer Health Activism
Progressive employers know that they are served best by health systems that prevent illness, promote health and swiftly restore vitality, productivity and functional well being to their employees and dependents. Health activated consumers increasingly recognize the role they must play to protect their health and to do their part to self-manage illnesses and injuries. Here again, employers and consumers will need to have ongoing, person-centered measures of change in health status to load care plans at the front end and to gauge the effect of care plans on health outcomes and costs.39

Electronic Health Records (EHRs) and Personal Health Records (PHRs)
Advances in health information technology hold great promise for improving care coordination, care effectiveness and efficiency. However, to realize the potential of EHRs and PHRs it will be necessary to incorporate selected patient-reported data to track and measure trends in health status (symptoms, function, health behaviors that contribute to health risk). This will allow providers to determine the impact of treatments and refine and revise treatment plans over time to achieve optimal, preferred patient outcomes.40

Computerized Adaptive Testing
The field of computerized adaptive testing (CAT) is advancing rapidly and is widely used for many large-scale national educational testing programs. This field is based on mathematical techniques, such as item response theory (IRT) and Rausch methods, enabling a computer to select items (or survey questions) to deliver to a respondent based on that individual’s prior responses so that the respondent’s score on a particular area of focus (such as knowledge of calculus or level of bodily pain) can be measured with high precision and parsimony (such as with a small number of items selected dynamically). Therefore, it is possible to decrease respondent burden without sacrificing accuracy of measurement. CAT methods are moving into health assessments and health measurement and have been advanced tremendously by the National Institutes of Health (NIH) and its investment in state-of-the art Patient-reported Outcomes Measurement Information System (PROMIS). PROMIS offers public domain “static” measures of adults’ and children’s health status and also makes “dynamic” CAT scoring methods available in an open source platform that anyone can use or adapt.

Collaboratories: Patient Reported Measures Trust
All of these emerging opportunities create an opportunity to form “collaboratories” that make use of patient-reported measures that are collected and used in a standard way to research and improve the outcomes and value of care and the science of health care delivery. In basic science, a collaboratory is a community of cooperating “laboratories” that share data and information and findings to advance scientific
knowledge. A collaboratory becomes a “virtual laboratory” connecting many scientists and research facilities to form a network with a shared aim. An iconic collaboratory is the human genome project. Using the models and methods described in this paper, we have the opportunity to construct health care delivery science collaboratories that work to study and improve the outcomes and costs of care.\(^4\) Dartmouth is in the early stage of building a health care delivery science collaboratory, called the Dartmouth Data Trust, which can bring together different streams of data, such as claims and electronic health record data, and patient-reported data, to understand which care models produce the best outcomes at the lowest cost for specific populations. The Dartmouth collaboratory is being designed and implemented to include Medicare and all payer claims data, selected data from electronic medical records such as diagnostic and treatment data, and a common set of patient-reported measures on health outcomes, patient experience and shared decision making. Figure 21 illustrates some of the key features of the Dartmouth Patient Reported Measure Trust.

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**Diagram of Dartmouth Patient Reported Measure Trust**
Health policy makers, payers, employers and consumers are all demanding that the health care system become more efficient and demonstrate its ability to improve the value of health-related expenditures. Value in health care can be defined as the quality of care in relationship to the costs of care and can be better specified by focusing on the health outcomes (or changes in health status) of individual patients and of populations in relationship to costs associated with health care and poor health over time.7; 11; 43

We believe that one effective way to address this problem is to embed patient-centered value measurement into the flow of clinical care using patient-reported measurement systems and improvement science to design, deliver and improve health care. Improvement science will be enriched and patient/population health methods will be improved if we take advantage of patient-reported data to feed vital information as health care is given and proactively use data feedback to monitor, improve and research care to achieve better outcomes, better care and lower costs.
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