APPENDIX

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Patient Generated Health Data (PGHD) Project
Introductory Meeting of the Technical Expert Panel (TEP)
January 14, 2013
12:00 pm – 1:30 pm ET

Objective: Produce a draft outline of input document for Meaningful Use Workgroup on enabling PGHD. NeHC will develop the full document and circulate for comment by TEP before February meeting.

Meeting Summary

Introduction

Jenna Bramble conducted roll call. List of attendees included at the end of this document.

Kate Berry asked for introductions of Chairs and TEP members.

Chairs of this group are Jonathan Wald (RTI), Eva Powell (National Partnership for Women and Families), and Danny Sands (Beth Israel Deaconess).

Project Overview

Jodi Daniel provided an overview of the patient generated health data (PGHD) project. In 2012, the Office of the National Coordinator for Health IT (ONC) commissioned a whitepaper on PGHD and the HIT Policy Committee also held a hearing. There has been a lot of interest in the discussion and moving it further into the policy arena though the meaningful use program. However, there is pushback from stakeholders about whether the issue is ready for primetime. This issue was included in the Request for Comment (RFC) on meaningful use Stage 3.

This group has been convened to help set up parameters, expectations and criteria important for the successful integration of PGHD into clinical workflows. The goal is to use this information initially to support the discussions of the HIT Policy Committee Meaningful Use Workgroup as they finalize draft recommendations due in April and to then support other efforts within ONC as they move forward with final rules for Stage 3 or outside of Meaningful Use. The group should consider best practices in using PGHD to create a policy framework related to what is outlined in the RFC and in the second phase, the group should consider strategies for a policy framework that covers other types of PGHD that may go past Stage 3 or may be outside of Meaningful Use .

Kate provided an overview of the project plan. She emphasized the importance of gathering examples around PGHD.

TEP Discussion

Danny Sands asked if it would be worth discussing changes in the reimbursement structure as it relates to PGHD. Currently, many physicians don't want to engage outside the office visit because the office visit is what they are paid for. However, as the reimbursement system changes, that trend will also change and may open the door for PGHD. He asked if the group should work under the assumption that the reimbursement structure will change.

Richard Upton suggested crafting a defined benefits statement around PGHD directed toward both the provider and patient, in which the group could address reimbursement.

Donna Cryer noted that there is value in the PGHD discussion even within the confines of the office visits. There is an immediate frustration from patients who collect this data on mobile apps [or in other ways] when physicians do not have the mechanism to incorporate the information into patient care.

Jodi said that overall we are talking about standards for behavior, not technology standards. We will never be able to incorporate data from a patient if we do not have standards for behavior, which can then make things easier from a technical and workflow/policy perspective. This discussion does not necessarily get to the reimbursement question, but we have to assume that there will be people engaged in the shifting reimbursement models and we should think about a policy framework working for both environments.

Mike Lardiere added that there is an ROI there to have patient data, especially in Federally Qualified Health Centers (FQHC), because it will help expand capacity. By monitoring patients offsite that would normally come in for visits, you can spend more time with patients that are sicker or have insurance to cover visits. Many FQHCs are dealing with a lot of uninsured patients.

Danny agreed that in the final report the group should pay attention to personal ROI for physicians.

Donna added that workflow is the big issue for this topic and creating behavior standards around that can be valuable. We should be thinking about prescribing policy that reduces burden on physicians.

Virinder Batra said that it is also important to look at how the physician needs to deal with the volume of data in terms of how they receive and respond.

Eva Powell agreed and added that the workflow must be manageable on the provider end and the patient workflow should also be considered. The group should talk through the workflow issues in ways that consider how the patient could make the workflow better for the provider. Patients need to be equal partners in their care and there are huge implications around that from a cultural perspective. The first shift is giving patients access to data.

John Mattison said that standardization and regulation can be liberating or stifling for innovation. The workflow issue is in a primitive stage of evolution, so rather than prescribing workflows, we should allow innovation to happen.

There is also a tangible issue that we should address has to do with issues around spoken and written language. For example, if you have physicians who are communicating and recording visits in native tongue with individuals, the people in that practice or system who do not speak that language do not have access to the information in that record or from that encounter. Safety standards around languages other than English might be good to consider.

Virinder added that workflow is different depending on the data. The group should define the categories of information that are coming from the patient and then think about the standards needed to get various types of data into the workflow.

Danny also mentioned the liability. The group needs to consider a physician's liability for data being generated outside of the office visit.

Jodi responded in saying that she hopes the group can think through some guidelines and expectations – not regulating, but providing best practices – to help providers not be so worried about liability issues. We should establish some standards of behavior for reducing anxiety and risk.

Chuck Parker suggested reviewing the regulatory framework that the FDA has implemented. It is important to ask what patient reported data means when combined with devices. The group should also consider state issues that have regulations in place that might prohibit the use of data from devices.

Jon Wald said that another challenge is identifying how PGHD will be used in legal, clinical and business environments. As we talk about that data flowing throughout those systems, we will reach the challenge of figuring out how different data scenarios are handled.

Holt Anderson added that the trust in the data and the level of data quality is a critical consideration. Perhaps we should start by looking at pilots that are working to ensure collection of quality data.

Jon said that identification of the source is part of the solution set. When PCAST was released, support for data collection was restricted to the atomic level. When you give consumers editorial rights, even if they didn't originate the data, that demands atomic-level metadata. The ability to have a machine-generated trail is also a critical element. Much of what the consumer directly enters will not be read with human eyes, but with machines. In that context, the original source becomes important to the quality of the data.

Donna responded that the fact that data has passed through the hands of the consumer should not automatically make it suspect.

MaryAnne Sterling added that HIMSS is currently looking at validity and reliability of data. This group should also be looking at PGHD through the lens of care planning since clinicians will be required to do this.

Eva also suggested exploring work of PatientsLikeMe in data reliability.

Virinder said that as we move forward with Stage 3 we should include an area where the patient is required to review data and send corrections in a standardized format.

Kate paused the discussion to summarize the main themes:

- Put parameters around what the group is talking about in terms of PGHD for purposes of the project
- Make sure that the group understands the workflow implications for the provider and the patient
- Put together a list of key issues (liability, quality and reliability of data, regulations) and examples of how to address issues
- Discuss PGHD in the context of reimbursement and other pressures
- Discuss the best ways to manage or implement PGHD that are not overly burdensome and supports care planning
- Understand who else is doing relevant work (HIMSS, PatientsLikeMe)

Kate provided an overview of the sections of the RFC for Stage 3 that mention PGHD. For the purposes of the first phase of the project, the group should consider section SGRP 203B, 204D and 207. She also reviewed the proposed scope of work for Phase 1 and 2.

- Scope Phase 1: Provider requested electronic data originating with the patient that the patient conciously gives to a provider, whether self-reported or dynamically generated from a medical device. Data can be clinical or non-clinical.
- Scope Phase 2: Patient initiated electronic data that a patient conciously gives to a provider, whether self-reported or dynamically generated from a medical device. The provider and patient should agree on how this data will be used to improve the clinical encounter. Data can be clinical or non-clinical.

Eva suggested a discussion around medication reconciliation with patient input. That is tied to 204D with revisions and amendments to the EHR.

Jodi agreed that electronic medication reconciliation could be within scope.

Michael Barr said that medication reconciliation should happen between clinician and patient, and that raises other issues in terms of automation.

Mike added that the group should be talking about behavioral and emotional data as well in the definition of PGHD.

Donna said that she had a problem with the qualifier "provider requested" in the Phase 1 scope. So few providers request PGHD at this point due to culture and it can often be the patient who originates the request. The group should focus on making sure that information is given in a format – whether it comes in passively or through an electronic device or viewed through graphs or trend data – that is easiest to incorporate into workflow at this point. There should be a focus on type of data and recognize that there is a difference between GI monitor or blood pressure information rather than paper notes and narratives.

Mary Jo Deering noted that since this first phase is related to meaningful use, doctors will actively need to consent to receive data, so there will need to be agreement from providers. Assuming providers will accept data is a given.

Eva said that by leaving the door open for non-clinical data we are looking at something that is somewhat confined, useful to all, and can be standardized and quantified. We should not only be thinking about typical data when we think about what data is important.

Danny agreed and said that there needs to be a taxonomy of PGHD in order to drill down and get it deeper.

Virinder added that the group should also define standards for patients actually using and sending that data to the provider.

Jon said that another way to narrow the scope might be to focus on workflow. Providers have established workflows for accepting data coming from the patient, but they may be inadequate. If we distinguish between information that will or might fit into an established workflow, those are things that

meaningful use can address clearly. Other data that wouldn't be regulated can go to phase 2. Let's start with areas where the workflows already exist and the regulations can have a greater impact.

Richard Upton suggested replacing "provider requested" to "provider encouraged." There is a potential loss for engagement if we use "requested."

Eva agreed that focusing on workflow makes sense. In addition, the group should note integration of high value data that might require some changes to workflow. There will not be a standard for much of this data and where workflows work we should keep them. Despite the lack of standards and definitions for this information, we should not ignore things that are high value or things that need to be happening concurrently with regulation development.

Next Steps

- Summarize key themes in the context of project plan and circulate to TEP
- Circulate the summary of comments on PGHD sections of the Stage 3 RFC
- Begin to identify categories of highest value PGHD as well as possible standards of patient and provider behavior, within the framework of the Stage 3 RFC.
- Collect examples of successful implementation of PGHD, especially within the framework of Stage 3 but not limited to it.

The next TEP meeting is February 19 at 12pm EST.

The meeting adjourned at 1:30pm EST.

Meeting Attendees

Name	Organization
Holt Anderson	NCHICA
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Pam Cipriano	Galloway Consulting
Donna Cryer	CryerHealth
Jodi Daniel	ONC
Mary Jo Deering	ONC
Jeff Donnell	NoMoreClipboard
Neil Evans	VA
Kathleen Frisbee	VA
Leslie Kelly Hall	Healthwise
John Hixson	VA
Mike Lardiere	Nat'l Council for Community Behavioral Healthcare
John Mattison	Kaiser Permanente
Elizabeth McKnight	Alliance of Chicago
Benjamin Moulton	Harvard School of Public Health
Chuck Parker	Continua Alliance
Erin Poetter	ONC
Eva Powell	National Partnership
Lygeia Ricciardi	ONC
Danny Sands	Society for Participatory Medicine
Richard Schwabacher	Quest Diagnostics
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Jenna Bramble at jbramble@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
February 19, 2013
12:00 pm – 1:30 pm ET

Objective: Produce a draft outline of input document for Meaningful Use Workgroup on enabling PGHD. NeHC will develop the full document and circulate for comment by TEP before February meeting.

Meeting Summary

Introduction

Jenna Bramble conducted roll call. List of attendees included at the end of this document.

Kate reported that Jenna Bramble will be leaving NeHC. Ian Hoffberg will be taking over support for this project from this point forward.

Kate provided an overview of the meeting objectives.

Discussion

Danny Sands suggested focusing on structured vs. unstructured data in the deliverable. Jon Wald also suggested identifying areas of PGHD that policy could impact.

Danny asked if the outcome of this work should be to propose metrics that should be used in this area.

Jodi Daniel noted that the group should not think about metrics as a standalone, but based on the experience of the group if there is intelligence that you have that would suggest metrics, they can be included. The group does not need to define metrics for each use case, but providing input on metrics based on lessons learned would be helpful. The group should try to capture operational best practices.

Donna Cryer noted that patients would welcome instructions for how to structure their data to be included in the EHR.

Virinder Batra referenced some work at Intuit where they are using pre-visit data from patients and moving it into the EMR in the CCD format.

Jim Walker proposed that at some point the group think in terms of a framework for executing on structured and free-form information that is informed by cognitive psychology and systems engineering.

Jon agreed and noted that the group seemed to agree that discussing both unstructured and structured data is important.

Neil Wagle referenced work at Partners Healthcare where they tried to operationalize structured data. It is harder for patients to understand how to enter data in unstructured ways and they could only make a case for integrating the structured information. There was no easy gateway through which to integrate unstructured information into the EMR, so they removed unstructured components from what we were doing.

Danny noted that there is an evolving sense of the nomenclature of PGHD. There is value to each of the different types of data, structured, unstructured, qualitative, and quantitative.

Jim added that is important to also consider structured and free form drawings.

Dick Upton commented on the difference between patient generated data and patient directed data. He asked how the group could consider data that a patient is transmitting from one clinician to another and if that is being addressed from an interoperability standpoint.

Virinder responded that HL7 is currently developing standards for patients in the CDA format. They are proposing that patient-authored documents carry a CDA header that identifies the information as patient-generated and instructs the provider how to make that information interoperable.

Danny asked if the group should narrow the scope to leave out directed information.

Jon asked if solving the data provenance challenge would take care of the issue of reliability between patient directed vs. patient-generated data.

Jim said that it would not solve the problem and the group should take both types of data into account. Patient generated data can be as sensitive and specific as clinician created data.

Donna noted that she liked the idea of data provenance and making the distinction between information coming from another physician office without being altered and information that is patient generated. However, there is always the risk of passing bad data even if it is coming from EMRs.

Danny suggested that the group say that the idea of PGHD and directed is arbitrary since it doesn't help us predict accuracy.

Neil encouraged the group to think about the business side of the transaction. Information is electronic and flowing toward provider organization. We assume it will be documented, but what kind of rules or processes do we think will always have to be envisioned to handle that?

Jim suggested starting with a process map.

Neil noted that there are two reasons for accepting information: verification (is the information accurate?) and acknowledgement (do we need to act on it?) Accepting data defeats the need for both of these. Verification is not practically possible and if we force providers to accept each piece of PGHD the sensitivity for actionable data will go down. The alternative is to have the data identified as PGHD after it goes in and then, when a provider looks at it, they can use guidance and skepticism to decide whether to trust the information.

Jim agreed and reiterated that it should be based on a process map that defines the information and a process management system that should be the destination. The PGHD should not be sent directly to the doctor.

Neil agreed that any provider accepting data into the record is not advisable.

Holly Miller cautioned that this process would require complete transformation in constant monitoring and the staffing model and workflow would be very different. The infrastructure needs to be in place before we regulate, otherwise this will not work.

John Mattison said that the bigger issue is giving patients the ability to manage themselves based on simple parameters (out of bounds or alerts would be elevated to providers). We also need to consider atomic level provenance metadata.

Jon referenced the anecdote of lab results. When labs are delivered to an office, there is a process for how they are treated and result in a set of possible actions. When a packet of PGHD arrives, should we be thinking about the set of possible actions and the processes that define who, when, what happens with each of those?

Richard Schwabacher clarified that lab results are very often acted upon by the patient before the physician's staff, so he cautioned against dictating the workflow. Quest has had success in providing actionable information to the patient and having the patient follow up with the physician. As a result, the patient is also providing information that is complementary to the clinical information, rather than the provider just having the clinical information itself.

Holly added that there should be a process for someone in the provider office to respond to the critical values.

Richard agreed, but said that the issue is having the patient know that information they have is something they need to act upon. In terms of disrupting workflow, clinicians embracing PGHD will find ways to integrate it and make it work. We should be looking at what blue button is doing and thinking about how that information should be communicated across a standard plane, rather than thinking about who should act on it and how to act on. We need to address what we think is the most important data that could be complementary to clinical information.

Mary Jo Deering suggested that for the purposes of Phase 1, the group should decide on a limited number of areas to address around providers being able to accept PGHD for high priority health conditions and save other areas for Phase 2.

The group suggested a list of potential areas to address in Phase 1:
Type of data - structured or unstructured
Format or data
Verifying source and accuracy
Documenting data
Acting on the data
Developing a nomenclature of all the different types of use cases

Gene Nelson suggested that the use cases focus on historical information and critical condition monitoring. The group should also ask what information the patient wants to provide and what information the provider wants to receive.

Jim agreed and said that the question is what is the information that the patient has that will be most important to the patient's care. The group needs to separate the deliverable into three things: the architecture that this will need to have if it is going to be what we want in the next five years (policies, soft-

ware), illustrations of what we're talking about that currently exist, and how they relate to meaningful use recommendations.

Jon asked how we come up with the lists of the top three things that are most important data for a provider that could be obtained from patients and top three that are most important from a patient perspective.

Jim said that we should ask what the patient knows that no one else in the world knows. Adverse effects could be one.

Donna said that she is wary of limiting types of data or fields we would be requesting. The real information lies in the differences across patients and conditions.

Mary Jo suggested that the group think about groups of data elements that are determined based on provider and patient mutual agreement.

Gene suggested considering elements under the categories of preventive care, acute problems, surgical problems, and chronic conditions.

Michael Barr added that family or economic issues (social determinants) are also critical pieces of information.

Jodi suggested that the group identify one use case that applies broadly, regardless of condition, so that PGHD is shown to be valuable and can apply to almost anyone who is presenting into the healthcare system.

The next TEP meeting is on March 11 at 12pm EST.

The meeting adjourned at 1:30pm EST.

Meeting Attendees

Name	**Organization**
Holt Anderson	NCHICA
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Pam Cipriano	Galloway Consulting
Kathleen Connors DeLaguna	CMS
Donna Cryer	CryerHealth
Jodi Daniel	ONC
Mary Jo Deering	ONC
John Hixson	VA
Robert Jarrin	Qualcomm Life

Name	Organization
Mike Lardiere	Nat'l Council for Community Behavioral Healthcare
Erin MacKay	Nat'l Partnership for Women & Families
John Mattison	Kaiser Permanente
Holly Miller	MedAllies
Eugene Nelson	Dartmouth Hitchcock
Chuck Parker	Continua Alliance
Danny Sands	Society for Participatory Medicine
Richard Schwabacher	Quest Diagnostics
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International
Jim Walker	Geisinger

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
March 11, 2013
12:00 pm – 1:30 pm ET

Objective: Standardize a way to approach the case studies to extract best practices.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Jon Wald introduced the document "Questions for PGHD Case Study Examples" circulated prior to the meeting.

Danny Sands and Jon Wald reviewed the goal of the project goals:

- We want a standardized way to approach to the case studies to extract best practices.
- Identify lessons we should apply to best practices.
- To review the list of questions and apply them to the case studies.
- Are these the right questions to be asking?
- What refinements do we need to make?
- Are there other perspectives that are important?
- Intending to be inclusive to capture patient (family, home care team) perspective and provider (clinical care team) perspective.

Jodi Daniel suggested that some of the questions in the provider section should also be asked in the patient section such as what are the workflow implications for the patient?

Danny and Jon agree that we should restructure the questions. We should break the questions down into Patient Perspective, Provider Perspective and a Parallel section that encompasses questions for both the Patient & Provider.

Virinder Batra suggested grouping or clustering the questions together into 3 or 4 categories. For example: Data, Process, Standards.

Neil Wagle suggested the idea of “Perceived benefit of providing the data, ie “What’s in it for me” for both the patient and provider is important to think about when it comes to getting both the patient and provider actively engaged in sharing information.

Jon Wald agreed stating that there has to be an understanding of value and perceived value for people to participate. For example a patient would think how is providing information going to improve my care.

Eugene Nelson was introduced as the expert on the Dartmouth Institute Case Study and provided insight on the study.

Dartmouth Institute Case Study Review
Reviewed by Eugene Nelson to test question set

Overview of Dartmouth Institute Case Study

The idea of this program was to provide team based care, a co-development of the feed forward feedback process. Patients making an appointment would be prompted to take a questionnaire; the patient would complete this survey at the spine center or at home prior to the office visit. The patient would access the Epic Portal MyChart to complete the survey. A summary report generated from the survey would be available for the clinician to review with the patient at the appointment. The summary would instantly evaluate and score the patients health status, physically and mentally. The summary would review the disability status, risk factors, and health trends in functional status over time. A care plan would then be established. When the patient would come for each subsequent visit, the patient would take the survey again. This would provide a longitudinal approach to trending the patients' health issues in relation to the care plan. This approach provided the clinical team a better understanding of how to develop an appropriate plan of care for the patient. Outcomes of the care plan would be based on the systems metrics, disability index, mental health status, and changes in physical function. That data would aggregate up to the Dartmouth public reporting system. This program became the basis for 13 spine centers funding.

Questions & Answers

Q: How will I be recruited, informed and supported to contribute data? How do I initiate?

Q: What tool/functionality do I need to be able to submit the data?

Q: At what point do I submit data?

A: The scheduler invites the patient to complete a survey at home prior to the office visit. To access the survey from home they would log into Epic Portal MyChart. The survey can also be completed in the waiting room prior to the appointment with the care provider, but not recommended.

Q: Do I have input into what data is collected?

Q: Who decides the form, amount, and content of the data (e.g. structured or unstructured)?

A: The data is structured through standard questions involving standard measures of physical and mental health. The data collected becomes a moving picture of the changing health outcomes reported by the patient.

Q: Do I encourage patients to access and correct the medical record?

A: This aspect was not in the scope of the Dartmouth example.

Q: What segment of my patient population do I implement this process with?

A: All patients of the spine center are enrolled into the program.

Q: What form of technology is required for providers to receive the patient generated information?

A: Access to the Epic Portal MyChart

Q: How do you achieve a high level of participation?

Q: When/How does the process become a standard of care within the practice?

A: The process is embedded into the workflow for the staff to utilize the questionnaire. If the patient does not have this info then the care team is unable to provide a thorough evaluation. The process was adopted as a cultural norm within the practice; the data evolved into a must have for the clinical staff along with the PGHD evaluated scoring metrics of the data.

Q: What is the process behind storing of data? Is the process accommodated by epic or is it proprietary to epic? Is the data available in a collaborative platform?

A: Current process is a Dartmouth team of Epic programmers used MyChart tools to collect and score the data then embed it.

A: In the Epic environment they wanted to mirror the platform that was already implemented at Dartmouth (as seen in the technical paper).

A: Open access software platform which is available to other health systems and health care environments.

Q: How hard or easy was it for other spine centers to take on this approach, what were the technical and cultural challenges?

A: The process has been adopted across many other spine centers. The software is available to health care programs.

A: First the process must be built into the patients' routine (cultural norm).

A: The scheduling workflow was altered to adopt the new process.

A: The clinical staff must commit to using the data and summary I the office visit.

A: The data must be displayed in a way that works for the patient and provider.

A: Interpretability – The scores must be easy to understand and explained.

Q: Who received/reviews the data? (a range of individuals? A single individual? How do we decide?)

A: Consent is obtained of the patient that it can be used by their care team, like any other clinical document.

Q: What is the obligation of the provider to review the summary report?

Q: Is the obligation the same if the patient does not have a scheduled office visit?

A: The data routes directly in to the medical record, even if the patient does not see the provider.

Q: What is done with the data, by whom and when?

A: The data routes directly in to the medical record, even if the patient does not see the provider.

Q: What expectations do I have about my role and my provider's use of my data?

A: The patient is expected to input the data and then the summary report is provided to the clinician and patient to review in the office visit.

Q: If a patient is unable to participate in the survey, what accommodations where made?

A: Friend or family member would help the patient complete the survey. If the patient does not have anyone to help then conventional history taking and assessment would be taken.

Q: What range of mechanisms can be used to make sure a patient is identified, authenticated, and authorized to send data?

A: Logging into the Epic Portal is the authentication stage.

Q: Does the patient have access to the data at anytime or only when with the provider?

A: Current process is to have the summary and data reviewed by the patient and provider together; future system is going to allow patients to view their health history at home.

Next Steps

Ian Hoffberg will develop a Categorization of Questions for Case Study Review

Danny Sands stated for next meeting we would like to take this same approach to review another case study and continue to refine questions.

Danny suggested creating Subcommittee on Taxonomy

- Danny and Jonathan will co-chair
- The following Technical Expert Panel members volunteered to participate
  - Neil Wagle
  - Virinder Batra
  - Leslie Kelly Hall
  - Holly Miller
  - Jamie Skipper
  - Richard Schwabacher
  - John Mattison
  - Jodi Daniel
  - Mary Jo Deering

The next TEP meeting is on April 11 at 12pm EST.

The meeting adjourned at 1:30pm EST.

Meeting Attendees

Name	Organization
Holt Anderson	NCHICA
Virinder Batra	Intuit
Kate Berry	NeHC
Kathleen Connors de Laguna	CMS
Jodi Daniel	ONC
Mary Jo Deering	ONC
Jeff Donnell	NoMoreClipboard
Leslie Kelly Hall	Healthwise
Robert Jarrin	Qualcomm Life
Jonathan Leviss	Rhode Island Quality Institute
Erin MacKay	Nat'l Partnership for Women & Families
Elizabeth McKnight	Alliance of Chicago
Holly Miller	MedAllies
Erin Poetter	ONC
Eugene Nelson	Dartmouth Hitchcock
Danny Sands	Society for Participatory Medicine
Richard Schwabacher	Quest Diagnostics
Jamie Skipper	HHS
Richard Upton	UPTONGROUP
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
Taxonomy Subcommittee
March 20, 2013
4:00 pm – 5:00 pm ET

Objective: Establish a common language to describe characteristics of patient-generated health data examples.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Danny Sands introduced the discussion by saying any categorization will be a work in progress, as new technologies arise and we learn more about PGHD. Our goal should be to create a framework that suffices for categorizing PGHD projects now and in the foreseeable future.

We will use a "top-down" and "bottom-up" approach. We will rely on expert experience and opinion to create a draft taxonomy, and then we will analyze PGHD case studies to attempt to categorize them according to this framework. We will then revise the draft taxonomy as needed.

Mary Jo Deering provided feedback from ONC for this subcommittee. Keep eyes on things that are critical, e.g. what information do patients and providers think is most important to their health and care. Also, make sure we have input from nurse practitioners.

Neil Wagle submitted his notes prior to the meeting. There are a number of different types of PGHD. Here is an example of how to arrange this taxonomy:

Verification / Data Entry
- Demographic information
- Insurance information
- Medication Reconciliation
- Allergies
- Family History
- Social History / Lifestyle Risk Factors (e.g. smoking)

Symptom / Functional Status Reporting
- Patient Reported Outcomes
- Adverse drug events
- Adverse clinical events
- Review of Systems

Biometric Information

- Remote vital sign monitoring (e.g. blood pressure, weight)
- Remote glucose or other lab monitoring
- Graphical information (e.d. telemetry)
- Nutrition or Physical Fitness monitoring

Images / Videos

- Pictures (e.g. rash)
- Video (e.g. gait)

Narrative

- Goal setting
- Journaling

Patient Experience of Care

- Satisfaction

If I had to pick 5 of these to start with, it would be very challenging.
Perhaps:

- Medication reconciliation
- Patient reported outcomes
- Adverse drug events
- Remote vital sign monitoring
- Pictures

Regardless of which 5 one would pick, I think that the policy treatment of each of these can be different, and I think it might help to be clear about which kind of PGHD we are talking about when we are discussing. For example, in terms of alerts/provider verification, you might want a clinician to have to acknowledge EVERY adverse drug event, but perhaps you would NOT want clinicians to have to verify reams of NORMAL vital signs (but you would definitely want them to know about abnormal/critical ones). All PGHD are not created equal in terms of how we need to treat them.

Patient role in Data Capture	Active	Passive		
Data Flow	Device-driven (push)	Patient initiated (push)	Provider initiated (pull)	Mixed
Request That Data Will Be Shared	Mutual	Clinician	Patient	Mixed
Synchrony	Asynchronous	Synchronous		
Data Type	Free Text	Structured Text (includes XML, CCDA, etc.)	Numerical	Other objects (image, audio, video, waveforms, etc.)

Next Steps

1. Finish refinement of Technical Taxonomy.
2. Discuss and refine Neil Wagle's Functional Taxonomy.
3. Discuss Mary Jo's ideas for perhaps another orthogonal taxonomy (or work these into one of our existing taxonomies).
4. Identify gaps.
5. Do "bottom-up" testing of our classifications

The next TEP Taxonomy Subcommittee meeting is on April 1 at 4:00pm EST

The meeting adjourned at 5:00pm EST

Meeting Attendees

Name	**Organization**
Virinder Batra	Intuit
Kate Berry	NeHC
Jodi Daniel	ONC
Mary Jo Deering	ONC
Leslie Kelly Hall	Healthwise
John Mattison	Kaiser Permanente
Holly Miller	MedAllies
Danny Sands	Society for Participatory Medicine
Richard Schwabacher	Quest Diagnostics
Jamie Skipper	HHS
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
Taxonomy Subcommittee
April 1, 2013
4:00 pm – 5:00 pm ET

Objective: Refine the technical and functional Taxonomy. Identify any gaps we have in the Taxonomy.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Jon Wald stated that we want to continue the taxonomy discussion, move from technical to the functional. From a bottom up approach identify key examples that will help us test if the taxonomy is descriptive enough. We should focus on data that patients and providers think are most important. Starting with the Technical Taxonomy what areas should we add?

Jon Wald said that before PGHD actually starts flowing we must first identify the data that is to be sent, or the patient must decide to start sending it.

Mary Jo Deering commented that there are instances the data could be upfront mutuality but there can be adhoc times. Once you have an agreed upon type of data there is no negotiation required for an upload.

Virinder Batra said the system can figure out the values in the red zone, based on previous outcomes, it is then up to the provider, it would go to what was previously agreed upon (Policy Driven)

Jon Wald asked if there are other dimensions we should add?

Neil Wagle asked if the data is stored in the health record in perpetuity or not?

Leslie Kelly Hall responded that once the data is accepted into the record the rules of the record apply. Accepted material are part of the record, nothing changes the legal constraints of the record.

Holly Miller stated that for all cases the physician should have the ability to pull the discrete data as they choose. It is important for it to be structured. Non-structured is important too and the data can be pulled into structured data fields.

Danny Sands commented that we are trying to figure out a way to discuss the current examples of PGHD, not a perfect scenario. Why/ how we can identify best practices?

Holly Miller said that within a linked portal the end user has the ability to pull data right into a note and edit it.

Jon Wald suggested we add a row that focuses on process of documenting an EHR. The Taxonomy will describe different options.

Jon Wald asked the subcommittee to now focus on the Functional Taxonomy. Are the 6 categories Neil Wagle provided clear? Are there any suggested changes?

Neil Wagle provided an example of how to structure the Functional Taxonomy

"Static" Information

- Verification / Data Entry
    - Demographic information
    - Insurance information
    - Medication verification
    - Allergies
    - Family History
    - Social history / Lifestyle risk factors (e.g. smoking)

Active Data

- Symptom / Fun3ctional Status Reporting
    - Patient reported outcomes
- Risk assessments
- ADLs
- Other PRO
    - Adverse drug events
    - Adverse clinical events
    - Review of Systems
    - Pictures / Videos
- Journaling
- Biometric Information
    - Remote vital sign monitoring (e.g. blood pressure, weight)
    - Remote glucose or other lab monitoring
    - Graphical information (e.g. telemetry)
    - Nutrition or physical fitness monitoring

Proactive Data

- Care planning
    - Goal setting
    - Preferences
    - Values
    - Advanced directives

Retrospective Data

- Patient experience of care
    - satisfaction

Virinder Batra commented that technology (video, picture) should be its own category. Not functional taxonomy

Neil Wagle responded that for example a picture of a rash is considered a symptom

Holly Miller didn't think it should be under functional taxonomy either

Jon Wald suggested that we take it out because it is in a technical area and it doesn't seem to fit here.

Leslie Kelly Hall suggested that we should introduce the patient view, a context of who I am

Neil Wagle suggested under narrative we have goal setting, journal, patient experience, and progress to goals

Jon Wald commented that Neil's suggestion is a distinction of the patient care experience

Virinder Batra asked that since a lot of these sections are structured data areas, does unstructured area fall under the narrative?

Danny Sands responded that the narrative still has a role, like journaling, it is not so much of what the patient is doing but why they are doing it

Jon Wald suggested that under goal setting we should have care planning activities. Does the group agree this is a reasonable functioning category?

Neil Wagle supported that idea. Neil asked if advanced directives and planning fall under that category?

Leslie Kelly Hall also agreed that under care planning we should have preference, values, and have a legal structure, but they are not mutually exclusive

Jon Wald thought it was clear that we see PGHD fitting into any aspect of a care process. There are no limits

Holly Miller agreed with Leslie and Neil, we should have another section that pertains to alerts to patient, prescription renewals, test, etc…

Leslie Kelly Hall asked if there is a different taxonomy on inbound vs. outbound data?

Jon Wald stated that there are differences due to the roll of the player

Holly Miller suggested an alerts section that is to provider vs. to patient

Danny Sands agreed that he can see that correspondence with prescription drug issues

Mary Jo Deering asked for a clarification. Why is an alert from the provider considered PGHD?

Leslie Kelly Hall responded that if there is an expectation for a response it should be considered. For instance do not take this medication, your response is required.

Jon Wald followed up by saying that it would be part of the feedback arrow in figure 2 of the PGHD Flow Diagram found in the White Paper by RTI International.

Mary Jo Deering said that this group has identified a unique use case, and may not be focused on what we are trying to achieve

Jon Wald felt that we are fitting a PGHD step into a more holistic process

Leslie Kelly Hall felt there may be an underlying document. Here is a structure that there are new communications, and automatic functions that are part of the overall landscape, but not necessarily part of this paper

Holly Miller wanted to clarify that medication verification is verification of what is actually being taken, and reconciliation is comparing 2 lists and determining what should be continued and discontinued. The patient will have their input and verify the meds list. With the idea of risk assessments the patient can enter a score on a depression scale; also a false risk assessment should be in here

Neil Wagle agreed with Holly Millers comments

Leslie Kelly Hall added disability living, self reported observations, and ABL's

Jon Wald asked the group what does this group think is most important to focus on? Should we test the taxonomy on an example?

Leslie Kelly Hall thought there was a big opportunity for preference sensitive care, for example the patient sees the importance of a colonoscopy but prefers not to do it.

Danny Sands agreed that we should encompass that with the patient preferences.

Jon Wald felt it highlights the difference of all the different types of PGHD, to asses' risk factors and monitor health, the decision by the patient is also very important.

MaryJo asked if informed consent is another area of PGHD? And does my decision to not have surgery captured as a preference?

The group agreed that it is a preference, similar to an advanced directive it captured by wishes and preferences.

Next Steps

Ian Hoffberg will update the taxonomy, Mary Jo Deering and Ian Hoffberg will apply to the Dartmouth Case Study

The next TEP meeting is on April 8 at 12:00pm EST

The meeting adjourned at 5:00pm EST

Meeting Attendees

Name	**Organization**
Virinder Batra	Intuit
Kate Berry	NeHC
Mary Jo Deering	ONC
Leslie Kelly Hall	Healthwise
Holly Miller	MedAllies
Danny Sands	Society for Participatory Medicine
Jamie Skipper	HHS
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
April 8, 2013
12:00 pm – 1:30 pm ET

Objective: Focus on near term deliverable to provide suggestions on how to achieve the MU Stage 3 recommendations based on real life examples and pragmatic guidance. Review and discuss the questions developed to analyze the case studies, the taxonomy work, and the case study examples can support development of practice guidance to help providers and patients effectively share PGHD.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Kate Berry started the conversation about the short term deliverable. She asked the panel for suggestions on how to achieve the MU Stage 3 PGHD recommendations based on real life examples and pragmatic guidance by reviewing and discussing draft document. The phase 1 deliverable is due week of May 20.

Mary Jo Deering added that the panel should put themselves in the shoes of providers, those who have no direction; here are good practices, this is not a policy document. What we are trying to be is helpful for the folks who need to implement this with no real knowledge.

Danny Sands felt it is premature to make recommendations on a handful of case studies not really reviewed.

Mary Jo Deering responded that any little bit helps, what we deliver right now is a first step, the panels best effort here is where we see promising practices. Initially it will be reviewed by the MU workgroup, they can be reassured there are discussions out there. If you are going to be a MU user here is the best we can offer you right now. A richness within the categorization of questions, and contribute to the good practices

Leslie Kelly Hall agreed that having meaningful questions to ask to deliberate on policy, and the questions are a good test case are an important deliverable.

Kate Berry reviewed the documents shared for today's meeting the first being the Categorization of Questions for Case Study Review. This outline is directly using the questions developed to review the real life examples and a lot of information that came through the taxonomy subcommittee. The second document is the PGHD TEP Suggestions Regarding Stage 3 Recommendations Related to PGHD , along with the comments from this panel this document will include the RFC HITPC gathered by the HIT policy committee and provided in a consolidated form from Mary Jo Deering to NeHC. The recommendations are SGRP 204B, SGRP 204D, and SGRP 207.

SGRP 204B
Provide 10% of patients with the ability to submit patient-generated health information to improve performance on high priority health conditions, and/or to improve patient engagement in care (e.g. patient experience, pre-visit information, patient created health goals, shared decision making, advance directives, etc.). This could be accomplished through semi-structured questionnaires, and EPs and EHs would choose information that is most relevant for their patients and/or related to high priority health conditions they elect to focus on.
Based upon feedback from HITSC this should be a MENU item in order to create the essential functionality in certified EHRs.

SGRP 204D
Provide patients with the ability to request an amendment to their record online (e.g., offer corrections, additions, or updates to the record) through VDT in an obvious manner.

SGRP 207
EP Objective: Use secure electronic messaging to communicate with patients on relevant health information
*EP Measure: A secure message was sent using the electronic messaging function of Certified EHR Technology by more than **10** percent of unique patients (or their authorized representatives) seen by the EP during the EHR reporting period.*

Comments/Questions?

Neil Wagel thought 204B and 204D are different from 207 and was not sure if this fits into the taxonomy

Danny Sands agreed with Neil

Jeff Donnell felt that it makes more sense to include 204D rather than 207

Leslie Kelly Hall commented that 207 and the Dartmouth testimony is how messaging contributed to overall health process, we do not have a way of constructing that message. Through messaging care toward mental health – observe and collect data and should be easy to consume in the EHR

Danny Sands asked that for 204D the issue of amendment is important, but is it really a PGHD issue?

Leslie Kelly Hall responded that since it is new information coming in, those inputs are important for continuity

TEP member stated that there is an importance of corrections, and of corrected data. One is an enhancement the other is correcting what the pt would recognize as error of their input

Virinder Batra added that information from patient, when a provider is sending CCD the patient may think the info the provider collected during the encounter may need to be amended

Jon Wald commented that the definition we have been operating under did not include 204D & 207

Leslie Kelly Hall added that there is a filter in place, and the provider is translating the observation. The source is just as important as the data coming from the data. Preparing, experience, goals, are all very important

Dick Upton commented that as a patient (204d) would like the opportunity to correct data and say it was not my intention or intent

Danny Sands thought that a lot of people do not see this as well placed in this document. Data mis-reported or represented by the provider is not found in the taxonomy, and it doesn't fit into the chart.

Holly Miller commented on structure for unintended consequences; with appropriate workflow structure the practices or patient will not feel overwhelmed. The more categories we include the more process we have to review as well.

Holt Anderson agreed that acute care setting patients do not get confused about process.

Leslie Kelly Hall added that a process section, and workflow section, is something we have not worked on yet, but important for the insertion. Process vs. Content needs to be reviewed. We should look at the current structure.

Jon Mattison suggested we operationalize the taxonomy in a simple way; certain things the patient should expect should be reviewed on the way into the chart and there are some things not accepted that will be a sub straight from decision support systems. 1) Direct file to chart, 2) file for review queue prior to chart. Once it has been reviewed then the provider is now responsible. We must have convenient PGHD expected instrumented for review, the other for direct insertion of the chart. It will help sort what questions belong where.

Jon Wald commented on the communication process. There are many avenues that are not regulated; if they are, then it is up to the individual to decide what is heard and documented. We should be careful not to think we can overly systematize every aspect. 1) Information providers are expecting require a process in place to handle, 2) information is offered by patient, welcomed but not expected, and 3) off the chart; an appropriate response is needed for information that we are not ready for and that we need to shut down this communication channel.

Mary Jo Deering felt it would be welcome to consciously scope what we want to include and what we turn in. If there is X # of categories of info we are not including under our promising practices for XYZ reasons. We can narrow the scope and focus on what is important instead of presuming our recommendations would cover all examples of PGHD. Carve out a manageable scope.

Dick Upton commented that he thinks this would be oversimplified. We should look at empirical data. For example please let us know of any adverse conditions (medications). Anecdotal – certain info that would need to be dealt with but this is inappropriate way when disseminated in this manner. Can this be beneficial (204d) in one area and it comes into play in the issue of errors? We should have an area that can contribute in keeping the information accurate; improving the input of data and information that can have a positive influence on the reduction of errors.

Danny Sands agreed and added that we have worked that into the taxonomy

MaryAnne Sterling noticed that the roll of the family caregiver is missing.

Kate Berry commented that 204b & 207 are narrow and straight forward that we can come up with best practices. Should we walk through those 2 or do we want to shift gears and review taxonomy. We should have something to suggest.

Danny Sands added that there is a huge amount of literature about 207. We have not looked at this, transport mechanism, but the use of the media has been written. Amendment process should be in place but out of scope of this group.

Mary Jo Deering suggested that the NeHC staff can take upon themselves for 207, 204D. Suggested the Geisinger study to abstract and come up with a format that could be useful, we will then find that 204B we will find some statements that will be surprisingly relevant to 207 and 204D

Virinder Batra suggested that for 204B and structured format could drive 204D

TEP as a whole agreed with Virinder's comment.

Jon Mattison felt there is a good legal president. The patient can submit as the information is viewed as incorrect, the amendment can be attached, but nothing should be deleted.

TAXONOMY DISCUSSION

Danny Sands reviewed the 1.5 version of the PGHD taxonomy document

Mary Jo Deering reviewed the taxonomy chart applied to Dartmouth case study. There is a glossary to review passive vs. active terms, also Push vs. pull. Most cases will be pushed but there will be instances of pull. "Sharing" who wants the data, similar to the data flow, we felt like sharing in this instance is for the internal (request of the data) remove share and reframe this, where the data is coming from, either the provider is asking for it or the patient is just going to send unexpected data.

Donna Cryer asked is there contemplation on pt perspective for the information to be sent to multiple providers (sharing of the data) ongoing access to the info? Is there a concept that can describe this growing sentiment around pt data that we want it sent in multiple directions?

Jon Wald responded that we should not limit the direction of the data, and that possibility

irinder Batra added that BlueButton keeps it in account and that it is possible to do. Patients should have a list of potential recipients. Working with BlueButton, automation patient defines which providers the provider should be sending the data to.

Mary Jo Deering added that consent for the provider to share with other providers is found under content. Structured text – structured questions led to the understanding that there was structured text. If the providers in MU 3 are required to identify the providers that are not then that would be an undue burden, and I strongly think there will be a backlash. If the group is in MU 3 then this group would say that info must be submitted in a structured format to make it executable. Functionality in the workflow (207) it could be something the group wants to highlight, structured drop down box for that kind of transmit to multiple providers.

Jon Wald asked the group to consider proactive vs. retrospective. If the data is visit centric, the patient's point of view may not be the same as the provider. Pre-visit info stands alone pretty well.

Kate 204B – thoughts on how we can approach those?

Jon Wald suggested we identify the top 3 or 5 important examples? Perhaps we can boil down to a list of examples.

Kate Berry followed up by saying with those examples we can then 1) guidance on how practices should approach it and 2) can be backed up from examples

Danny Sands added that we do not have a lot of examples, the ones we do are at major medical centers. How do we apply to a small practice?

Leslie Kelly Hall suggested that we develop a baseline; this a very important step, and the markets will change/adapt

Jeff Donnell commented that from an ambulatory practice level we can focus on feedback on amendments. 1) Data continuity of care (medications, and allergies) and the patient corrects inaccuracies. 2) Practices that forward lab reports or imaging, patient will see that report and say this is not my radiology report; incorrect scan in my record. Most of our clients are accepting PGHD, data used for preregistration, data online in advance, same data they would do on paper in the waiting room they realize it is superior. We provide a tool set so they can selectively import their Data. We should come back with a reasonable first steps.

Holly Miller wanted to remind the group that the more options and menu items we have the more variability for practices to use IDN's for staff to select what is important to their patients, more opportunities for the market to develop.

Virinder Batra added that forms are a based import, CCD, they can be sent to the EMR partners

Mary Jo Deering asked Jeff Donnell (nomoreclipboards) do your practices ask the patients to fill out every visit or just at first register?

Jeff Donnell said they encourage them to go back and make updates, and encourage to look at the health record and if there are issues let us know.

Holt Anderson commented that patient satisfaction I presume has gone up when the patient can have that impact.

Jeff Donnell said they are starting the process to measure satisfaction. They are seeing that with that opportunity satisfaction does increase. A tool like this has been able to get some of the tougher patients more engaged.

Holly Miller said that is comparable to well known literature. Patients who have access to the record without the ability to correct it lead to frustration. Ability to update leads to higher satisfaction and greater accuracy.

Leslie Kelly Hall added that checks and balances are present when the patient has the opportunity to correct.

Next Steps

Ian Hoffberg will update the PGHD TEP Suggestions Regarding Stage 3 Recommendations Related to PGHD

The next TEP meeting is on May 6 at 12:00pm EST

The meeting adjourned at 1:30pm EST

Meeting Attendees

Name	**Organization**
Holt Anderson	NCHICA
Virinder Batra	Intuit
Kate Berry	NeHC
Donna Cryer	CryerHealth
Jodi Daniel	ONC
Kathleen Connors de Laguna	CMS
Mary Jo Deering	ONC
Jeff Donnell	NoMoreClipboard
Frank Fortner	Iatric Systems
Leslie Kelly Hall	Healthwise
John Hixson	VA
John Mattison	Kaiser Permanente
Elizabeth McKnight	Alliance of Chicago
Holly Miller	MedAllies
Danny Sands	Society for Participatory Medicine
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
May 6, 2013
12:00 pm – 1:30 pm ET

Objective: Technical Expert Panel member Kathleen Frisbee is presenting the PGHD work the VA has presented to the Office of the National Coordinator for Health IT (ONC). The group will then discuss how to prioritize the data elements that are most valuable and feasible, and to identify the priority health conditions and priority elements of patient engagement that can be supported by those data elements.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Kathleen Frisbee performed VA presentation by Kathleen Frisbee followed by a Q&A session.
Kathleen Frisbee said the apps start soon, I will be happy to come back in 6 months to discuss findings; we are doing focus groups on the population; social networking app was most requested, then the my-journal application. One use of the PGHD is to help people better manage chronic condition (e.g. PTSD).

Workflow:
- When does PGHD become part of the record?
- How to distill PGHD to be actionable?

Policy Issues:
- Timing/requirements for when providers look at PGHD (e.g. highlighted values are brought to their attention)

- Standardize data before publishing in record

Danny Sands observed two approaches to the data in the presentation; 1) Data involving health care team, and 2) data independent of the health care team

Kathleen Frisbee responded that both approaches have the same data elements, depends on situation when and whom sees the data. Similar to writing prescription, we would like you to prescribe use this app because we think it will help you better manage your condition.

John Mattison cautioned when creating incentives to push toward next step. The partitioning of data, other than consent, "ownership" of data, is a challenging concept…for the immediate stage we do not have the decision support systems we will have in 5 years, what really affects health, and maintains, are the micro decisions made by individuals not supervised by a health professional. Analogy (inpatient) physicians do not review nursing notes. There is a wealth of data there not being reviewed, we are having trouble shifting from consumer owns vs. provider owns. "Ownership" of data means who is responsible for doing something with it. It can be overwhelming to providers if they think they are responsible for doing something with all the data.

Jon Wald added three points. 1) Policies, upfront, how to provide care, covers legal and other wise – need to be identified and used proactively. 2) Slide 4, policies are defined by the VA on the left, policies are pre-negotiated. On the right there is murkiness about the policies. How do you come to clarity on policies on the portal data? 3) Evaluation – as you get into this initiative, can you provide your comments on how you evaluate?

Kathleen Frisbee responded to Jon by saying that your second point relates to John Mattison's comments that "Ownership" of data means who is responsible for doing something with it – can be overwhelming to providers if they think they are responsible for doing something with all the data, it is important to have clear responsibilities stated. To your third point the family care giver pilot, research study looking at the 10 apps, how the impact has been on caregiver burdens, culmination of apps that most closely align to preparedness, burden, etc…initial data analysis will be done in 6 months

Leslie Kelly Hall commented that patients do not understand who owns the data. Patients believe if an organization is sponsoring a vehicle for them to provide information then they expect that the data is being managed, reviewed, and uploaded to the EHR. Patients are disappointed to learn it is not being looked at or used. Need to set expectations and plan for how to do this in the future.

Kathleen Frisbee responded that we have that problem now. Data mining engines would be great, to use data to inform patient and provider, we want to be at this level. In general, most patients want it shared with the provider and used by the health system.

Virinder Batra asked what data is standardized?

Kathleen Frisbee responded that medications are standardized to RxNorm, labs are standardized to LOINC.

Robert Jarrin asked why do you think the social media app is so popular and who is looking for it?

Kathleen Frisbee responded that care giver population is taking care of seriously ill patients and want a support network of others experiencing what they are experiencing.

Discussion of Expectations of Near Term Deliverable for TEP

Danny Sands asked ONC to please explain what is meant by "high priority" health conditions and to whom they are considered to be high priority?

Mary Jo Deering responded that based on the comments to the RFC, others were seeking clarification of "high priority" health conditions. It would be helpful if the TEP can provide its perspectives and rationale for what should be considered High Priority and why.

Donna Cryer added that "high priority" conditions suggest those conditions for which the care is highly dependent on patient reported information (e.g., migraines, irritable bowel syndrome) focus on these types of things as more likely to have an impact. The clinical decision is driven by accuracy of patient reporting. Not as much on blood work, but more PGHD. Conditions that are driven by the provision of PGHD.

Jon Wald asked ONC – we think there are many situations that have high value to care process to have patient-provider sharing of information (decisions that are very sensitive); The VA has 10 apps; they are tackling this in a broad way, not with a simple list. Is it our goal to come up with priorities we want MU 3 to make it possible to manage many kinds of data? Or more detailed list that we want to collect specific data for specific condition?

Mary Jo Deering responded that the TEP is tasked to make strong clinical decisions on things that may be out of scope. If we can stop short of that 2 prong approach; the outcome of our work should be targeted to providers who are very intimidated about receiving PGHD and where patients are potentially being harmed because their data is not used to inform their care.

We need to follow a two part process:

- Phase 1 –inform regulatory environment and process (this puts limits on us; menu choice for MD's, show them)
- Phase 2 – use expertise of all TEP

Jodi Daniel agreed with Mary Jo Deering; we would like the TEP to identify types of patient generated information that would be helpful and valuable to providers that cut across multiple conditions. Focus on the kinds of information that cuts across multiple disciplines, conditions, and a set of data elements that patients are uniquely positioned to provide that adds value to their care. This is an opportunity to change the paradigm of how feasible it is for MDs to start reviewing data. Determine what information providers really want that patients really want to provide.

Holly Miller agreed; this should be done at the practice level in partnership with their patients so it can focus on what they are working to improve in the context of shared decision making. This varies by specialty and patient population. The more open we can make this approach as a shared decision process between patient and provider the better. We should have a shared decision measure, for instance does the patient understand their choices? With an outcome goal of improved care and adoption of PGHD

Leslie Kelly Hall commented that there is a nexus point, all have high prevalence and relevance, and then we can move to more specific areas. Here are my suggested data points:

Short List:

- family health history (nice to have but not essential for all conditions)
- current medications being taken
- patient health history

More expansive List:

- Pre-encounter
    - Health Risk Assessment (depending on condition)
    - Functional Assessment
    - Patient, family and other personal care givers - Goals

- Post-encounter
    - Patient, family and other personal care givers – Reported outcomes

Mary Jo Deering commented that there needs to be a process; how to accommodate any data, it is possible that the phase 1 report may choose to highlight a particular set of information. Most widely accepted, patients and providers, we encourage providers to have this conversation with patients; this will in turn drive requirements that certified EMRs must accommodate. Are there standards that are pretty close to adoption to get the data flowing?

Jon Wald added that secure messaging is one of the most promising for PGHD to be exchanged. Already part of certified EHRs, it is flexible, construct messages to make it readable, from a workflow aspect; however it is also a lot slower for specialized applications.

Mary Jo Deering agreed that secure messaging is already in MU as a delivery mechanism. Secure messaging supports the need for patients to access their record, and request changes in the record.

Virinder Batra added that with secure messaging there is a good chance these are structured data elements

Mary Jo Deering reminded the group that technical aspects are phase 2. How would the TEP like to approach the content issue?

Michel Barr commented that we need to think with the end in mind, if free text it could be lost. This will influence what types of data are requested.

Kate Berry suggested a straw man approach. 2 lists – a short list (TEP) including family HX, pt HX, med list, and a long list including – functional assessment, goals, reported outcomes, hip or knee replacement, heart failure, etc…

Jon Wald added that a typical practice does not put effort into getting the family history now so they probably will not do it in the future.

Michael Barr responded that this could prompt those practices to request and follow through with obtaining the family health history. The pre-encounter data, and post-encounter data are all important

Jon Wald suggested we do away with those kinds of buckets and thinking. One thought is taking the time dimension (previsit, intervisit, post visit, interval visit) and breaking it out a little bit. Instead of have the data elements, like medication use, and show it in time context we create a table with columns for these timed constructs, rows for the data element. This could be good for patient engagement and priority health conditions.

Michael Barr suggested adding another layer, who on the clinical team should be reviewing the data? This could be multiple different time tables. It should be left to the practice to determine who, and any information that is coming in, infrastructure should look as similar as current workflow

John Mattison said it is important not to qualify data under who should be looking at it, also when they look at it. These are display issues, not the quality of the data.

Michael Barr agreed but there is a belief in actions that they need to do everything. In terms of examples in the narrative we can identify who should look at it.

Recap for group what the minimal comments subset is

- family health history (nice to have but not essential for all conditions)
- current medications being taken
- patient health history

NeHC will circulate a request for volunteers to iterate on the data element grid and share with the TEP. Leslie and Virinder volunteer to be in small group.

Next Steps

Ian Hoffberg will circulate a request for volunteers to iterate on the data element grid and share with the TEP. (Leslie Kelly Hall and Virinder Batra volunteered during meeting)

The next TEP meeting is on June 10 at 12:00pm EST
The meeting adjourned at 1:30pm EST

Meeting Attendees

Name	**Organization**
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Donna Cryer	CryerHealth
Jodi Daniel	ONC
Kathleen Connors de Laguna	CMS
Mary Jo Deering	ONC
Jeff Donnell	NoMoreClipboard
Frank Fortner	Iatric Systems
Kathleen Frisbee	VA
Leslie Kelly Hall	Healthwise
John Hixson	VA
Robert Jarrin	Qualcomm Life
Michael Lardiere	National Council for Community Behavioral Healthcare
Erin MacKay	National Partnership for Women & Families
John Mattison	Kaiser Permanente
Elizabeth McKnight	Alliance of Chicago
Holly Miller	MedAllies
Eugene Nelson	Dartmouth Hitchcock
Chuck Parker	Continua Alliance
Danny Sands	Society for Participatory Medicine

Name	Organization
Richard Schwabacher	Quest Diagnostic
MaryAnne Sterling	Sterling Health IT
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org *to amend the list.*

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
Table Subcommittee
May 24, 2013
3:00 pm – 4:00 pm ET

Objective: The subcommittee will be working on a table that is intended to provide a way of organizing and prioritizing the PGHD elements and timing of when it should be provided (e.g. pre-encounter, post-encounter, between encounters)

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

There seemed to be a general consensus that medical allergies, medication list, family history, and current problems and issues were appropriately at the top of the list of things that providers wanted to know

However there was some dissent on whether it was wise to focus on these areas when they were already ensconced in practice

Michael Barr was concerned with doing too much. While he understood the four groups were important, he felt it would be better to focus on other things that would have more incremental value.

The rest of the subgroup felt that the four categories were important and the patient was more likely to engage in his or her care when filling out such information prior to visits

The group suggested exploring transition encounters -not as part of the table

Triggers of information gathered

The group suggested modifying the table to clearly indicate categories that would be important to the patient during specific encounters (pre-encounter, all encounters, post-encounter, etc.) as it would vary from the provider

- Main question:
    - What information would always (or, almost always) be welcomed and accepted by the provider, if offered by the patient?

- Answer: Information that includes…
    - Safety-related
        - Medication List
            - Medication (history, current)
            - Medication Adherence (includes OTC)
            - Medication Reactions/Symptom Reporting
            - Validate Medication Reconciliation – DETAILED
            - Medication Updates, (Non)adherence
        - Medication Allergy List
            - Allergies (e.g. medication, new reactions, history of non-tolerated medication)
    - Treatment plan -related
        - Information the provider had requested
        - Recent changes that might prompt a change or reconsideration of the treatment plan
            - Biometric data (e.g. Blood Pressure, Blood Sugar, Imaging, Weight, Smoking Status, Exercise, Temperature, Nutrition, Heart Rate, Oximetry, Spirometry)
            - Chronic Disease Care/Data
    - A new patient concern
        - Unexpected Worsening Symptoms
        - Information deemed very important by the patient
    - Administrative and important
        - High Impact on Care Process
            - Advanced Directives
            - Key demographic information – updated contact or insurance information
            - Preferred facilities/locations (i.e. pharmacy, clinic, hospital)
            - Insurance Information
        - Caregiver / Care Team/ Support Roles Contact Information
        - Communication Preferences
            - Communication Channel Preference;
            - Permission For Sharing Information
            - Cultural and Language Preferences

Next Steps

Ian Hoffberg will update Priority PGHD Data Information document and circulate to TEP for next TEP meeting.

The next TEP meeting is on June 10 at 12:00pm EST

The meeting adjourned at 4:00pm EST

Meeting Attendees

Name	Organization
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Mary Jo Deering	ONC
Leslie Kelly Hall	Healthwise
Robert Jarrin	Qualcomm Life
Richard Upton	UPTONGROUP
Jonathan Wald	RTI International

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
June 10, 2013
12:00 pm – 1:30 pm ET

Objective: The goal is to make as much progress as possible toward reaching agreement on the PGHD Good Practices and PGHD Priority Information materials.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Mary Jo Deering stated that the 1st phase effort will be presented as a PowerPoint with the people working on Meaningful Use. As the panel moves forward into phase 2 we can start to provide more detail into the discussions. Thank you to all for your comments and feedback thus far.

Jonathan Wald took the group through the PowerPoint slide deck. He introduced it as an early draft deck, and we are looking for feedback from the panel during this call and through the end of the week. The panel's feedback will be found in the next version of the deck next week. The timetable is still flexible on when to get a finished product to the ONC. Reminds the panel that the Phase 1 deliverable is not comprehensive but a good introduction into what has been reviewed by the panel to this point. Jon reviewed each slide and opened the floor up to comments

Slide 1 – Title slide

Slide 2 – a high level of what we mean by PGHD – 1st bullet extracted from the white paper, 2nd bullet explains that the info is broad and changing, the 3rd bullet the term PGHD is a relatively recent but the idea is old, 4th bullet - opportunity to capture needed information

Neal Wagle – 1st bullet – This is a critical point for people to refer to. This pertains to not just data coming from outside the clinical visit; there is data coming directly from the patient or designee at the time of visit that they have recorded in between visits.

Slide 3 & 4 – here are examples of PGHD to help bring the less experienced provider along

Virinder Batra suggested examples of clinical decision support that are required by current regulations; there should be data points, from patient, associated with system triggers to some extent

Neal Wagle suggested pt reported outcomes, symptoms and functional status should be considered

Robert Jarrin suggested adding medical grade weight scale

Jon Wald concurred that we should add a 3rd and 4th slide listing these examples

Danny Sands – 1st bullet; we should state, upfront, that this includes caregivers and designees

Leslie Kelly Hall stated that we need better systems to be able to make changes, observations or results. If it is PGHD we must emphasize that we have the opportunity to accept or decline PGHD into the EMR; we need a better systems to identify which information is important

Daniel Sands commented that we need to make a distinction between data that a patient provides under a care plan vs. data patient communicates outside of one

John Mattison added that chart errors are fairly common which require a significant amount of changes to the EMR. Would like to see us work on wordsmithing this in a positive way

Danny Sands noted that just because data is being submitted it does not mean the physician is the one who needs to be reviewing it

Susan Woods commented that it is important to identify who the intended target is. For instance a record change/correction request could be intended for the office staff and not the physician. This type of scenario fosters Danny's point that there is too much info for the clinical team to solely be responsible for

Jon Wald shared that when he was at Partners HealthCare only 1 in 10 messages actually went through to the physician, he agrees we need a system that allows the information to flow efficiently

Slide 5 – Best uses of PGHD

TEP suggested we add Cleveland Clinic Foundation to Organizations bullet

Jon Wald noted that we could attach case studies to this slide so people can review the information in more detail

Slide 6 – These are really important, at no point should you not have a policy throughout the flow

Erin MacKay suggested a sub-bullet added to the patient, family, and other personal caregivers section that clearly addresses the need for policy in regards to emergency situations. How the patient can reach out to a human at the facility or practice and that they know what to do if they do have an emergency.

Leslie Kelly Hall added that patients are pretty good at deciphering between urgent and non-urgent issues and agrees policy should be built into the process

Danny Sands commented that we need to be careful at assuming what patients do and do not know. There are patients with low health education levels, and low socio-economic conditions that do not have the ability to make such distinctions on emergency and non-emergency related issues.

Jon Wald added that policies are important but this is why it matters, there are really good practices, we have to balance through supplemental materials

Holly Miller suggested a sub-bullet saying explicit instructions on what information is important and what is not

Mary Ann Sterling commented that initiation of PGHD may very well come from family member or personal caregiver, it is very important to make it clear; especially since it is not readily accepted in today's culture

Slide 7 – acknowledgment that you cannot get away from measuring, assuring, managing security issues; accounts; channels of communication; it must be done in a secure way

John Mattison would like to see a narrative of what the purpose is of this slide on the top; he is concerned, as is, it may confuse providers who want to accept PGHD

Slide 8 – concerns around PGHD that we wanted to acknowledge; when concerns are addressed successfully PGHD can become routine

John Mattison stated that perceived risk for being accountable for missed information may need a separate slide; we are going to be accountable

Holly Miller commented that we have the common concerns from a provider point of view but we should also have the patient point of view.

Some patient concerns offered by the group are:

- security breaches
- shared information with payer
- physicians who refuse to accept PGHD
- waiting period for physician to see patient data
- unmet expectations of where/who/when the data is being reviewed
- family member access
- policies for addressing access for juvenile

Slide 9 – highlights things that typically happen outside the care setting; a model view

Panel agreed this slide looks good

Slide 10 & 11 – Preparing for PGHD

The panel suggested additional items to add to the Preparing for PGHD slides:

- new patients you are trying to collect new visit information from to facilitate a valuable encounter focused on efficiency of care
- Information that resides in one system and not another

- Educating, training and supporting patients about PGHD, in order to build the trust it should be a face to face conversation and not a pamphlet
- Managing expectation
- Marketing to the individual or to a large market

Slide 12 – Information of value, aligned with the data information slide (slide 21)

John Mattison stated that the context of the data is crucial; we should aim for a list of data information that would be exemplar

The group looked more closely at the question: “What information would always (or, almost always) be welcomed and accepted by the provider, if offered by the patient?” The group agrees we should word-smith this better.

Leslie Kelly Hall suggested the phrase information from any age group in any circumstance

Michael Barr offered the use of sets of data that are considered consistently useful

Mary Jo Deering commented that she thought the group accepted that data is contextual; in addition, is there any data that a physician would never refuse; we should look at data not to prioritize it but to highlight key elements. Should we consider removing the word priority if that is considered explicit?

Slide 13 – a listing of the types of technologies being utilized

Slide 14 – consequent actions that may or may not happen, based on context and policy when receiving PGHD

Slide 15 – submission technologies that are currently being used

Mary Ann Sterling stated that there are still very large areas of the country that are still relying on paper

John Mattison commented that PGHD will become more useful as we have more flexibility in the way it is transmitted, submitted, communicated

Virinder Batra suggested that data via a structured format and or structured forms is better and should be mentioned at a high level

Slide 16 – PGHD can be reviewed by any care team member, triage is valuable and important, and documentation decisions are varied and are policy driven

TEP thought we should make a clear point that data can be incorporated into the EHR but does not have to be accepted

Slide 17 – Jonathan Wald used the ICU as an example of how to look at this slide an environment that has high volume integrated automation and other special considerations.

Slide 18 – panel feels that as technologies develop these QI points are interesting future goals

Virinder Batra commented that the legal rights of the patients are evolving along with the technologies

John Mattison stated that until we have real time analytics, similar to the ICU (great example) as we have it in use all day every day, but until we have that similar construct, pt triggers, etc…the next couple of years will be very impactful on how we are reviewing this document. We need to highlight the reality of what is current and how it is evolving

Jonathan Wald opened the line up for any additional comments on the phase 1 deliverable.

Jodi Daniels added that she would like people to think about what are the technical capabilities that we want to have in the technologies section so it can support providers who want to do PGHD; technical capabilities of a device perhaps; what can be built into the policies?

Next Steps

Ian Hoffberg will collect additional feedback from the TEP until June 14. A revised version will be provided to the group by June 21.

The next TEP meeting is on July 29 at 1:00pm EST

The meeting adjourned at 1:30pm EST

Meeting Attendees

Name	**Organization**
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Pam Cipriano	Galloway Consulting
Mary Jo Deering	ONC
Jeff Donnell	NoMoreClipboard
Frank Fortner	Iatric Systems
Leslie Kelly Hall	Healthwise
Erin MacKay	National Partnership for Women & Families
John Mattison	Kaiser Permanente
Elizabeth McKnight	Alliance of Chicago
Holly Miller	MedAllies
Chuck Parker	Continua Alliance
Danny Sands	Society for Participatory Medicine
Richard Schwabacher	Quest Diagnostic
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP

Name	Organization
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International
Jim Walker	Siemens
Jonathan White	AHRQ
Susan Woods	VHA

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
July 29, 2013
1:00 pm – 2:30 pm EST

Objective: Phase 1 is complete and the TEP's initial findings were presented by Jon Wald to the HIT Policy Committee Workgroup on Consumer Empowerment on July 18. Phase 2 will include development of a report on how practices can prepare, prioritize information, and incorporate PGHD into their practice, and will focus on emerging opportunities and issues beyond Meaningful Use. The TEP is asked to brainstorm important topic areas or domains, anticipating advancing PGHD in the future.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Kate Berry updated the TEP on what has transpired since the June meeting. Highlights included presenting the TEP with the phase 1 deliverable for feedback and comments, organizing background reference materials and working closely with ONC and co-chairs to prepare for presentation to HIT Policy Committee Consumer Empowerment Workgroup.

Jon Wald, MaryJo Deering and Jodi Daniel debriefed the panel on the phase 1 presentation.

MaryJo Deering stated that on behalf of the ONC they were very pleased and the presentation was very well received.

Jon Wald provided a review of the presentation. He presented what is meant by PGHD, what the concerns are for patients and providers, policies and processes, and a high level grid of organizations and activities to make a point that this area is already in play and growing. Then discussed the process view, and examples of PGHD (safety, treatment, new pt concern, etc...) He then emphasizes the key points 1) this area is highly contextual, the TEP found that it was important that not every area applies to every context. 2) Noted slide 17 non-specified vs. specified PGHD. He also commented that Christine Bechtel's summary was in line with the panels views that there is a strong message that context is everything, PGHD is important for safety, efficiency, and care management. Also that PGHD involves functional areas of receiving, reviewing, responding and recording information – key areas, important parts of the process, not sure how it will be addressed in MU but it was nice to hear it back from her since these are consistent with the TEP comments.

Erin MacKay commented that it was important to keep in mind that underserved populations may have a hard time collecting PGHD and we should keep those populations in mind.

MaryJo Deering summarized next steps for the MU workgroup. On 7/30/13 the Meaningful Use Workgroup will have preliminary recommendations presented from the Consumer Empowerment workgroup. Then during the 8/7/13 meeting of the HIT Policy Committee the MU work group will present all of stage 3 draft recommendations to the full committee for input. Links to these meetings were provided in an email by MaryJo Deering on 7/29/2013. Recordings and transcripts will be available on the ONC website and updates will be shared with the TEP once they are available.

Jodi Daniel commented that there are many steps to still go, Christine leads the MU workgroups, and is the voice for these recommendations.

Jon Wald added we have a wonderful expert panel contributing to this work, and thinks the outcomes of this group are important and influential.

Jodi Daniel thanked everyone for all their thoughtful input thus far. ONC is looking in-house on how we can build on the phase 1 deliverable to provide guidance and information for those who want to start moving forward with their PGHD initiatives.

Jodi Daniel commented that phase 2 will be a much broader scope. We should look at how we are thinking of PGHD. What are some of the practices and areas that do not fit into a regulatory framework for MU where we can provide thoughtful insight on those kinds of opportunities? (i.e.: emerging technologies, providing examples, and good practices) Anything that comes through the TEP we want to run through the policy committee so we can think about how best to do that. Outside of just MU, we expect this group can feed these ideas into the consumer empowerment workgroup later in the year. We want to encourage the use, development, and acceptance of PGHD on a broader scale. What are some of the other ways we can help motivate actions to have the patient be an active participant in their own care management? We are taking the boundaries off and letting this group identify what we should be focused on and how/what we can encourage beyond MU stage 3.

Brainstorming session

Underserved

John Mattison revisited the earlier topic on underserved populations. He requested any good documents on the subject to be circulated to the group; he is working on white papers for the White House on this topic.

MaryJo Deering referenced the NORC project with Geisinger. It took place in western rural PA, and that in the pilot most participants would be considered underserved. There has been no disparity of ability or interest in these populations.

Danny Sands commented that the underserved should be part of what we consider but not a central theme.

TEP agreed that we create a system that will work for the majority of people, rather than the minority of people able to have access to these things

Registries

Gene Nelson commented that we have state of the art registries and a wealth of PGD that is part of these registries. Some of the data can be helpful and some could really benefit scientific community incorporating PGD. For instance clinical registries could help for comparative effectiveness research and practice improvement; also when appropriate (i.e.: chronic problems, depression, joint replacement, etc…) are required PGD on outcomes. This could be an area for thought, work and development. Some professional societies help meet certification requirements, and practice improvement.

Neil Wagle liked this idea. What are other uses of registries? As we use PGD one question is how often do we keep track of how, when and which patients we reach out to. What is the appropriate time frame to reach out to these patients and how can we use registries to manage this outreach?

John Mattison responded that he has done the architectural design around this and has a slightly different view given we are moving toward personalized medicine. That it should be less about being on a registry but more on specific conditions and attitudes. He is wary about using registries for outreach. John is supportive of tracking progress of certain populations, but wants us to be mindful of constraining "personalized care" if outreach is to the patients via the registries. He does not like the idea of burdening registries when there is a longitudinal personal record.

Data Sharing and Transparency

Comments were raised about what is the domain of people that share data on their behalf? How do we orchestrate a provenance of sharing data? What about the scenario that someone else shares data on their behalf?

John Mattison is currently working on filing IRB applications on exactly that issue (i.e.: facebook data)

Virinder Batra commented that we need more connections of data steams for example a patient monitor may send in data directly to the EMR. How can we get these to work together, and to maintain the interest and engagement of the patient? They will not send or use data if they are not engaged in the process and help out the effort.

Sue Woods encouraged the group to think about the patient entering information, the value of the information, and how the patient will benefit by better managing their care.

Jon Wald added that transparency is important. For example, the patient should know what registries they are on.

John Mattison commented wouldn't it be nice if the healthcare systems cared for a whole person rather than parts of a person listed in registries.

Danny Sands encouraged the brainstorming mode we are engaged in. We want to generate ideas; what other areas seem really important as we imagine PGD at scale? What other ideas pertaining to the patient, caregiver, family, provider or data?

Neil Wagle reinforced the idea of the power of pooling our data. The more data pooled the more powerful it is. How do we create architecture of data sharing? Sharing functional status information, maybe we should focus in a specific area? Pooling identified data to learn more about our populations?

Danny Sands thinks the idea of PGHD falls apart if we do not have a shared commitment from the patient to improve their health or quality of life.

Mike Lardiere commented that there is a continuum here, some are engaged, and some with serious illness may be more engaged. We need to push the value back to the patients.

Health goals vs. Cost

Gene Nelson stated that benefiting a person's health is central. It is possible to extend it to encompass the idea of end use, the idea of utilitarian good through least cost. He is concerned about outcomes but also the cost to achieve those outcomes. For example PGD insight on outcomes that is most important to me as an individual, along with a population, but also the direct and indirect cost to the consumer. If I have back pain I can get speedy recovery with least time out of work that it is good for me. End user value, patient reports, indirect cost of care, how quickly do I achieve my goal with the least amount of care.

Opportunities to Add Value to PGD

Jon Wald asked the panel to think about your organizations; do you see opportunities for small changes that could occur that would allow scale and value of PGD to jump up significantly?

TEP provided the example of blue button plus which gives people a starting point.

Jon Wald asked how a patient portal can be helpful?

TEP said a patient portal can make it easier for people to share their information.

Jon Wald asked how to encourage patients to submit PGHD?

Danny Sands stated that it depends on the patient.

Gene Nelson said little things make a big difference. For example, Jon Watson at Dartmouth has a program called howsyourhealth. The patient's information can be shared with their clinician. Activation as an individual allows me to manage my health problems. Healthconfidence.org that takes self health confidence as an indicator to pay attention to; it may be scaled up in Massachusetts. British Columbia also has a program to take howsyourhealth as a consumer based personal health/assessment plan. They have seen an increase in elderly engagement.

PGHD in Mainstream in Five Years

Jon Wald asked the group to think about what will be mainstream in the future.

Virinder Batra suggested that big data will be mainstream and will allow multiple streams from the patient and other places, like registries, to be merged together for patient to look at.

Gene Nelson said in 5 years telehealth will be mainstream.

Sue Woods would like to see things like tracking blood pressures, manually entering data or wifi enabled devices, record amendment recommendations, and more access to clinical notes as becoming mainstream and for patients to be able to send comments that become part of the record.

Frank Fortner added that since Meaningful Use is causing providers to have a portal, this means that in 3-5 years there will be a huge population of people with information on a portal. What we are seeing today (i.e. fitbit, jawbone) these areas will naturally converge, portal and apps being able to talk to each other and pull data from multiple sources.

Robert Jarrin commented that in 3-5 years there will be data harnesses (ECG, skin temp, mobile telemetry, emergency response systems, etc…), and software (money readers, posture monitors, asthma sensors, medication adherence, etc…) that will drive the market place if the EMR allows the upload of this information into the EMR.

Holly Miller commented on the importance of reimbursement policies to drive provider and consumer behavior.

Erin MacKay suggested that patient's goals be incorporated into the clinical process in 3-5 years

Kate Berry thanked the panel for the discussion and ideas. We will compile a meeting summary and begin to build a work plan for the next phase.

Next Steps

Ian Hoffberg will compile a meeting summary and begin to build a work plan for phase 2.

The next TEP meeting is on August 26 at 12:00pm EST

The meeting adjourned at 2:30pm EST

Meeting Attendees

Name	**Organization**
Holt Anderson	NCHICA
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC

Name	Organization
Pam Cipriano	Galloway Consulting
Jodi Daniel	ONC
Mary Jo Deering	ONC
Neil Evans	VA
Frank Fortner	Iatric Systems
Robert Jarrin	Qualcomm Life
Michael Lardiere	National Council for Community Behavioral Healthcare
Erin MacKay	National Partnership for Women & Families
John Mattison	Kaiser Permanente
Elizabeth McKnight	Alliance of Chicago
Holly Miller	MedAllies
Gene Nelson	Dartmouth Hitchcock
Danny Sands	Society for Participatory Medicine
MaryAnne Sterling	Sterling Health IT
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International
Susan Woods	VHA

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
August 26, 2013
1:00 pm – 2:30 pm EST

Objective: The group will review a draft outline for the final report. The TEP will review the outline and provide additions and refinements based on what they think will make the final report most valuable. The group is asked to consider what are current key technologies, education, policy landscape, research gaps or additional work that is needed to advance PGHD in the next 5 years.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Kate Berry reviewed the agenda for today's meeting. Goal of the meeting was to review the list of items that came out of the brainstorming session and ask what the current key technology, education and policy landscape for these ideas. Also, for that same list of ideas what is the key technology, education, policy and research gaps or additional work that is needed to advance those items in the next five years? With time permitting Chuck Parker will present his thoughts on an approach to organizing patient generated health data (PGHD) that may be helpful as we work toward the final report.

Danny Sands asked if the panel has reviewed the PGHD TEP final outline draft.

TEP responded that they have and would like to walk through the outline.

Danny Sands felt that this was a good first pass at trying to frame up the final report. Danny then went through the topics found within the outline to start off the discussion to whether it is structured appropriately.

Virinder Batra believed that the "Trends and Technology" section should be a separate section.

Danny Sands asked the group upon thinking of the flow of the document, what if we reviewed it as a high level here and then have a more expanded section in the appendix?

TEP as a whole feels that this section is very important and it would not be appropriate as an appendix. It should be a separate chapter in the final write up and there is some concern that it may get lost in the appendix section.

Jim Walker commented that this section to him is a mix of needs and technologies.

Robert Jarrin thinks that the term “Big Data” needs further clarification.

Additional trends:

- Clinical decision support
- Social & demographic
    - Greater reliance on technology
- Clinical trends
    - Nursing shortages
    - Physician migration (organization, and location changes)
    - Record migration (physicians and patients keeping up with where there records reside)
- Patient participation (need for efficient processes to increase patient participation)
- Healthcare landscape changing from fee-for-service to fee-for-value or quality

Danny Sands confirmed that the group thinks we should make the Trends and Technology section a separate section and that other trends that are not technology focused but more cultural like aging populations, consumerism, etc…should be a separate chapter.

Robert Jarrin noted that previous work from the Institute of Medicine shows that technology trends can ease some of that burden placed on patients and providers.

Dick Upton stated that there is a tremendous burden on patients to ensure their data follows as providers migrate from one system to another.

Jon Wald added that there is a trend in the defunding of healthcare; most employer funded insurance and services will be transformed.

Danny Sands commented that there is a burden on providers and patients

Jim Walker suggested the concept that for patients who self manage, and use PGHD they should only have to gain access to a professional when they need to; we should be able to collect info from patients that is highly accurate and that can be fed directly to the healthcare professional with limited or needed interaction unless an intervention is required.

Erin MacKay stated that with binary communication we will overwhelm the providers; instead we should have more collaborative care, self care, and care coordination. How do we create and redistribute the work to co-produce healthcare?

Jon Wald would like for us to add health literacy into the trends section; comments on the size of the burden may not be so large if there is a shift toward self management by patient; literacy will be significant and important roll to include.

Holly Miller added that not only health literacy but also language; there are barriers for a collaborative care platform when we think about language, access to technology, unwilling providers, unwilling/incapable patients; there are always outliers, and we can identify them.

Danny Sands commented that if we envision a redistributed system, and in dealing with a population that has limited literacy, what does that mean to the system we are trying to design?

Holly Miller added that those same issues exist today, if there is access to information then they have the opportunity to widen their support system.

TEP agreed that we need a rebuilt systems that demands less literacy on behalf of the patient

Virinder Batra added that it should be easy to use, allows the patient to create their own structure, and the system will automatically code the data and it can be readily absorbed into the EHR.

Dick Upton commented that there is a major issue with educating patients and their rights. They need to understand what information the patient owns and their access to information when the information is transferred from one provider to another provider and when a provider migrates from one system to another system.

Jon Wald agreed that is a good point. The flow of information that is necessary for PGHD to move from a source to a clinical decision arena helps unblock the barriers to allow information to flow to all areas.

Dick Upton added that there are two points to consider. The first is the patients' rights to their data and information. The second is the standardized processes to allow the information to flow from one system to another when trying to follow a provider who migrates to a new health system. This is a trend we will see more and more as the culture changes. Also, the business side will change in a marketing aspect as providers fight for the market share; the records have to be able to move freely from one group to another. Perhaps there is room in the appendix for the legal aspect of patient right to know (HIPAA).

Ben Moulton asked where does shared decision making fall in this document? Is it part of the education section? There is am IOM white paper coming out in the fall and thinks this should be a separate section. When patients have a specific diagnosis they should have access to information to make informed decisions

TEP agreed that shared decision making is important, as patients become more educated and there is an increase in behavior change it will lead to involvement. Shared decision making is found in the value and benefits section. That section should be moved to the top of the document.

Jim Walker added that the treatment plan, as language, is associated with the physician/nursing plans. There is a need to have content and technologies that will allow a patient to work out their own goals in a way that could feed into the conversation with their provider and clinical team.

Sue Woods asked the question of how do we differentiate data going out and true PGHD coming in. The context of the tools patients and caregivers will be using; do we want to have a larger context discussing different functionalities?

The group discussed messaging of the final report. There are many things that we are discussing that are very important, but not specifically PGHD. The title of this report is about PGHD so if we took everything out that isn't PGHD and made a note that these things are critical to think about it would make it a more powerful paper. We can include aspects of patient engagement, care, and functionality and restrict PGHD to the rest of the document.

MaryJo Deering commented that in the future, 5-10 years from now, there will be different definitions of PGHD in regards to these trends. In the future it will be a larger context.

Dick Upton suggested that one way to streamline the paper would be to discuss the PGHD and then get into the management of the data (rights, blue button, etc…)

Jon Wald feels this is an important point. There is so much to do with the information when it appears. Does it make sense to think in different levels? For instance PGHD is a narrower scope, with a big impact on patient engagement which makes it a broader one. Other things like sharing records on line can do a lot for patient engagement which in turn makes it more important and likely to have PGHD as part of the big picture.

TEP discussed the idea of case studies and scenarios to share the vision of this group; where PGHD will add to the value of care, outcomes and cost.

Leslie Kelly Hall suggested a crawl, walk, run scenario. For example walk is represented by "sharing of information", run can be "community of collaborative care". There is a natural evolution.

Danny Sands commented that within his practice it isn't necessarily a linear process. PGHD will not always be empowering to consumers. There are instances where physicians want to use PGHD to monitor patients and tell them what not to do.

Ben Moulton used the example of an annual physical. The patient should be able to look at what has been written to ensure that what they think was important should be recorded

TEP discussed HIPAA regulations

The patient has the right to request an amendment to the record. The health care provider or health plan must respond to your request. If it creates the information, it must amends the information if it is inaccurate or incomplete, if the provider or plan does not agree to your request, you have the right to submit a statement of disagreement that the provider or plan must add to your record

Danny Sands noted that once information is in the record, the physician is then responsible for it.

John Mattison added that there is a looming flood of information that exceeds what humans can review. We must abandon the historical notions; we will very soon be in a place where it is impossible for a human to be responsible for all the data. How do we control what is coming in and what are we accountable for? There will be a new legal precedent in the future.

MaryJo Deering commented that the concerns section should be at the top of the document. When PGHD is implemented appropriately, concerns are address and the liability is reduced and greatly mitigated. The group should build on the reality that John Mattison is discussing. If a practice makes a decision to specifically scope what they are prepared to receive, even if that leaves out some data the patient would have like to submit; what is the legality at that point?

John Mattison provided a use case example for the group. A diabetic patient and physician group agreed to monitor and review the data via a mobile application. When the patient went to a new health system the new system said they do not cover it. This is considered to be a violation of quality of care. The growth of data is exceeding the industry's ability to accommodate it and provide clinical support. There is a rising gap of what is potentially useful and our capacity to use advanced decision support systems. It is a question of legal precedent vs. institutional policy, and the legal aspect is not going to be very pleasant.

Leslie Kelly Hall added that these things are going to evolve, and we will have multiple systems interacting; value based care - an ACO is not hurt by the information that they have but rather the information that they don't have. The ACO needs to invite as much data in as possible. As we get to a value based services, there will be evolving systems to sort the data.

Virinder Batra asked if there are guard rails we can provide for EMR's to make it a common denominator to start. What are the support systems that should be part of each EMR?

Dick Upton asked how do we get the providers to act on the data?

Sue Woods commented that we struggle with the assumptions; we need to create tools for patients and caregivers to collect data and information for their own purposes. Smart tools will help them monitor themselves.

Jon Wald agreed with John Mattison comment on the depth to community standard of care. The patient can generate some very fancy data however the patient may not have the experience or ability to comment on that information. If the data and information is not within the physician's scope or understanding then they will have to help the patient find someone to provide answers and insight.

Holly Miller suggested we show the value in the form of use cases (marketing), demonstrate where these ideas fit and would be of value.

Leslie Kelly Hall stated that there are very few things that automatically go into the record where the EHR administrator has not chosen to accept it. The information still comes into an inbox; we will have a range of use cases that show the transactional level (crawl), partnership level (walk), and a collaborative level (run).

Danny Sands asked the group if we should only be discussing the value in the use cases, or should we be illustrating where problems occur?

Sue Woods suggested another perspective. We want patients to provide amendments, and comments related to levels of their satisfaction. From a health systems perspective we want performance metrics.

John Mattison liked the idea of use cases. It speaks to a larger audience, and is a very useful model to communicate (market) what is relevant. Inclined to have use cases 1) state of the art today, where it is going; focus on evolving evidence on what data. Evidence based studies will help shape the market. As one pattern of what we know today, what we suspect for long term. 2) Dilemmas and unstable state where the evidence bases are iffy at best; scenarios where it is easy for a patient to be harmed or for a provider to be liable.

Erin MacKay suggested we could demonstrate a fully flushed out process in place and the value vs. a use case where there the process is flawed and the pitfalls, safety, liability, and dilemmas that can occur.

Danny Sands agreed that one or the other, or both approaches make sense. He just wants to ensure it does not look too much like promotional materials. Want it to reflect the high level of thought that this group has expressed. We have challenges, issues, literacy, and liabilities we can address upfront which will make this a more credible document at the end.

Jim walker suggested a way to do it is to start with the goals we are pursuing. Current trends, likely short terms trends, and then things that will support and intervene that would make them counterproductive.

Holt Anderson asked if we have a method for collecting comments on this work. Engaging the public and doing something with their comments?

MaryJo Deering stated that the best timing to brief the workgroup is middle to late October. We should plan to bring recommendations in November. The first round can be a PowerPoint and we should focus on what we can get to in October. Once we present our findings we will get input from the workgroup, and public comments. We can openly solicit on the call and follow up with an email address for additional comments. Then afterward, 4-5 wks into December, we will provide a polished up final report.

Chuck Parker presented a quick over view of his thoughts on how we could organize the data. Solicited vs. non-solicited data, and how it is being generated (i.e secure messaging, device data). The suggested model was provided to the group and it could help the subcommittee for building use cases.

	Connected Device	Structured User data	Unstructured User data
Solicited data (provider requested or established process for capture)	Consumer/Patient monitoring (Device data, limited user manipulation, secure, reliable, prescribed, policies and procedures are established)	telephonic or messaging based request for structured data (Information entered by patient relative to condition (i.e. glucometer readings, blood pressure, weight, symptom, meds, questionnaires)	Non-structured data (Unstructured information provided by patient/consumer at request of provider. Phone call or secure messaging. Visit requests, lab follow ups, subjective information on condition)
Unsolicited data (patient/consumer sends data not requested by physician	(Devices that are purchased by consumer or employer) captured at home through self-monitoring, extended caregiver or employer sponsored. Data may be structured and stored in PHR that can be transmitted or exported	May be data collected through a smart phone app or employer sponsored program. Also would include Weight Watcher's like sites.	Data sent from consumer or patient without a request from Provider or healthcare entity. May be origination of an e-visit.

Jon Wald requested the TEP to send the co-chairs and NeHC any ideas that they may have in regards to use cases; please provide one or two bullets so we can start on that approach. An opportunity to express what you would like to see as a use case and we can draw it out.

Virinder Batra suggested we should we have a subcommittee.

Volunteers for the Use Case Subcommittee:

- Virinder Batra
- Frank Fortner
- Holly Miller
- Chuck Parker
- Danny Sands
- Jonathan Wald
- Susan Woods

Next Steps

Ian Hoffberg will schedule a Use Case Subcommittee meeting and collect from the volunteers their use case suggestions. Ian will also update the draft outline for the final report.

The next TEP meeting is on September 23 at 12:00pm EST

The meeting adjourned at 1:30pm EST

Meeting Attendees

Name	Organization
Holt Anderson	NCHICA
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Jodi Daniel	ONC
Mary Jo Deering	ONC
Frank Fortner	Iatric Systems
Leslie Kelly Hall	Healthwise
Robert Jarrin	Qualcomm Life
Michael Lardiere	National Council for Community Behavioral Healthcare
Erin MacKay	National Partnership for Women & Families
John Mattison	Kaiser Permanente
Elizabeth McKnight	Alliance of Chicago
Holly Miller	MedAllies
Benjamin Moulton	Harvard School of Public Health
Chuck Parker	Continua Alliance
Danny Sands	Society for Participatory Medicine
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP
Jonathan Wald	RTI International
Jim Walker	Siemens
Susan Woods	VHA

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
Use Case Subcommittee
September 13, 2013
3:00 pm – 4:00 pm ET

Objective: The context of this subcommittee is to include in the final report some representative scenarios to help inform the reader of what are some of the key examples of PGHD and illustrate those. In pursuit of that goal this subcommittee submitted some use case scenarios. We will go through the submissions, and ID the key aspects we want to use when putting a final set of use cases in the final report.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate provided an overview of the meeting objectives.

Discussion

Subcommittee Use Case examples

Susan Woods requested that the first thing this group should do is distinguish between patient generated information vs. patient directed exchange of information. Making this distinction will decide how the data is treated as we review the use case examples.

The Subgroup agreed on a working definition:

- If the data flows from one source system to another system, where the data is unalterable by the patient, family member or personal caregiver, then it is to be considered "patient directed". If the data can be altered or touched by the patient, family member or personal caregiver in anyway, then it is considered "patient generated".

The group agreed that we should keep the technology aspect at a high level since the transactions are being done on many platforms across many different environments.

The scenarios should be consolidated when appropriate if the process and outcomes are the same for the specific use cases.

We must be cognizant of the fact that the transaction of the data may be similar but the workflow within the clinic, i.e. who reviews and updates the information, may be very different based on urgency and importance.

Verification is a very important aspect. There is some data that does not require validation, such as family history. There is some data that does require validation, such as change in insurance, or an update/ change in medication. For that kind of data someone has to verify the information is accurate and valid.

The group agreed that there should be an overall general statement that different data will be handled by different practice staff members. There is much variation on who will review the information and we should provide different scenarios that will illustrate variations, implications, and how the data has different levels of implied urgency.

Automation in the workflow will be something that will be more prevalent in 3-5 years. Not all data entered by the patient requires follow up. The roll of automation is very important in terms of relieving the load of the practice staff from having to review everything. It will also provide reflexive feedback to a patient when appropriate.

System alerts that are associated with the automation will allow a practice to set specific parameters on the data being received. A practice staff member will be alerted when the data is urgent, out of the norm or other set parameter designated by the practice. This alert system is another way to relieve some of the concerns the practice may have about having to review the large amount of data. (Holly Miller cited the Cleveland Clinic blood glucose alert system).

EMR systems have the capacity to set data levels that are normal for the patient and adjust per patient so the usual out of range value can be flagged when necessary. Along with structured symptom lists that can drive an alert for the practice staff. Setting up parameters for each individual patient is a large work stream within itself, but computers will make that workflow stream lighter.

In 3-5 years the computer and this kind of automation will be the first thing to intercept data coming from the patient. There will be algorithms that will compare data to previous data found in the EMR. It will filter and then triage the information to the appropriate person for review.

As a group we should also determine, within the use cases, if the information requires a face to face encounter with the patient, real time response or asynchronous. These levels of response carry different levels of work streams, heavy vs. light, for the practice. For example the patient needs clarification on the instructions for their medication or allergic reactions. There are identifiable risks or consequent actions that no one would want to miss due to urgency of the information.

Next Steps

Ian Hoffberg will consolidate the use cases provided by the subcommittee and write up notes from today's meeting to provide to the TEP for September 23 meeting.

The leadership group will discuss how to move forward with the examples, vetted by the TEP, for inclusion in the final report.

The next TEP meeting is on September 23 at 12:00pm EST

The meeting adjourned at 4:00pm EST

Meeting Attendees

Name	Organization
Virinder Batra	Intuit
Kate Berry	NeHC
Mary Jo Deering	ONC
Frank Fortner	Iatric Systems
Holly Miller	MedAllies
Danny Sands	Society for Participatory Medicine
Jonathan Wald	RTI International
Susan Woods	VHA

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
September 23, 2013
12:00 pm – 1:30 pm EST

Objective: TEP will be updated on the Use Case Subcommittee work, review the anticipated drivers affecting PGHD to identify high level gaps and priorities that should be addressed. The TEP will revisit the TEP generated list of areas of additional work that is needed.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Jon Wald provided an overview of the meeting objectives.

Discussion

Jon Wald reviewed the agenda. A short summary of the work the Use Case Subgroup did last week, spend some time reviewing the anticipated drivers affecting PGHD to identify high level gaps and priorities you think should be addressed, and to return to the TEP generated list that address areas of additional work that is needed.

Jon Wald discussed that the Use Case Subgroup reviewed 8 examples, ranging from sharing health maintenance information, Blue Button correction scenario, updating patient symptoms and medications. We also heard from Susan Woods on the work being done at the VA, and biometric monitoring, etc…We tried to organize the scenarios into a consistent format so they can be looked at side by side.

The content from the Use Case Subgroup will be organized so the scenarios form a reference point in the final report. It may be an appendix or in the body of the report. Intent of the use cases is to show the breadth, but also detailed examples of PGHD, the workflow associated with it, and illustrations that can help the reader understand some of what policies and future implications might be.

Dick Upton asked about a glossary of terms/taxonomy that the group had worked on previously and has not seen that work come back around, are we still working on defining a list of terms and the taxonomy? He is working on device/software development with EHR/device companies and some of the language being used is not consistent between the clinical, business, and patient-side. For example some of the terms are taxonomy, longitudinal plan of care, data sharing, big data, interoperability, telehealth, secure messaging, amendments, patient portals, etc… These terms are common to us but on the commercial end of business and the business process side, the language is different in terms of understanding.

Jon Wald responded that this is a really good point but a really hard area to address because there is so much heterogeneity.

John Mattison suggested that taxonomy implies that there is a relationship between terms vs. a lexicon which is just terms and definitions. Taxonomy and the relationship between terms require a context of use. The variations in taxonomies are similar to the variations in data models between systems. Suggested a simple lexicon of what we mean by these terms will help differentiate for the audience

Dick Upton commented that we have a great opportunity here to at least give a definition of what we think taxonomy is and it will have an impact as people move forward with PGHD and embrace our final report. For instance interoperability does not mean interconnectivity. If we gave a definition it can help establish a norm that does not currently exist.

John Mattison supported that and suggests that we do not propose these terms to be standard definitions, but rather this is what we mean when using these terms.

Dick Upton added that some of the terms can be accepted more broadly, and if there are more accepted definitions of the terms then we may want to redefine what we are using.

Jon Wald stated that what we do in terms of a lexicon will be influenced by how the final report shapes up and what the scope of that report is. We will note what Dick Upton has suggested and make sure that in the final work product that we have defined the terms that we think are import for understanding the report and important for others who are trying to work in this area, and as what John Mattison suggested without getting too mired up in the detail work that may be beyond the scope of what we are able to do. The leadership group had reservations on how far we can get calling it a taxonomy. The comments today underscore that.

Gene Nelson added other terms such as patient reported measures, patient reported outcome measures, patient reported experience measures should be added to the potential list. As for the report and the scenarios/use cases, who is the target audience for this report?

Jon Wald stated that the immediate audience is people who are involved in stage 3 Meaningful Use objectives and measure development, the consumer empowerment workgroup under the HIT policy committee; they received a presentation on phase 1. The second part of the report, which is more future oriented, and is not restricted to stage 3 Meaningful Use, the ONC is intending to have that for a broader audience.

Mary Jo Deering added that the final report will include phase 1 and phase 2, because we have important findings about process, valuable content and feasible approaches to mitigate risk and set mutual expectations. The final report will be on the ONC website as a standalone document as a resource.

Gene Nelson reviewed the drivers diagram, and with respect to the MU, there are things that are imbedded. Key terms such as transparency, measurement for accountability, outcomes measurement and tracking based on PGHD all seem pretty important for stage 1, 2 and 3 and where MU is going to transform healthcare.

Jon Wald reviewed how to read the diagram (slide 4 in PowerPoint). Items in "black" were items from prior discussion with the TEP. The items in "blue" were added recently to the list based on materials that we have reviewed or abstracted from case examples, etc…It is not a highly structured list, and may be incomplete but the idea was to take the things we are considering that will impact PGHD in the future, especially things that may increase value or volume or cause changes or impacts we would want to focus on in the report. Right now there are 4 areas Technology Changes, Medical Practice Changes, Patient Activities and Societal Trends. These trends are not mutually exclusive. What should we add? What does this panel notice that is missing? Are there areas that need to be underscored because they will have powerful impact?

Mary Jo Dering added that this is a list of trends that will stimulate PGHD

TEP comments on Diagram

We should point out in our report that this is not an exhaustive list

Have a disclaimer that this is an informaticians view of trends; would be appropriate for context

The panel agrees that we should change the names of the categories from "Medical Practice Changes" to "Healthcare Delivery Changes" and "Patient Activities" to "Patient and Consumer Activities"

Technology Changes: Enhanced use of standards, requirement standards, bodies around interoperability, and requirements around EHR technology

Patient and Consumer Activities:

Patient portals - Concern for many patients with complex conditions is trying to interact with multiple patient portals for multiple practices. Process perspective, patient and clinical, we should keep this concern in mind

It will not get easier with multiple layers of technologies

Identified targeted patient goals and Shared Decision Making, "Intelligent care", "informed self-management"

Societal Trends:

Increasing trend of Smartphone use among majority of US population with high penetration (mHealth task force, lifeline program should support fixed and mobile broadband for Medicaid patients. Wireless ehealth solutions should be available for patient care by 2017)

Reliance on older technology for connectivity/communication among key segments of the population, make sure we are not excluding any populations

Patients who cannot afford cost of care; shift from “volume” to “value” care (measurement, payment)

Growing numbers of family/personal caregivers directly involved in care.

Healthcare Delivery Changes:

Identified targeted patient goals and Shared Decision Making, “Intelligent care”, “informed self-management”

Care teams responsible for coordination and engagement of entire team of care

The TEP agrees with the information found on this diagram. We will produce a cleaned up version to the group for additional input.

Jon Wald transitioned the discussion to slide 5 of the PowerPoint. What policy areas, human performance, technology improvements, research, measurement, and PGHI content will be important to understand, develop to consider, and to explore? As we think about PGHD becoming more common and routine in the future landscape.

TEP comments on PowerPoint slides 5-11

Policy Areas (slide 6)

Provider-side engagement: Strategies are likely to vary with segmentation based on Business side (varies by payer) and the Clinical side (admin staff, clinical staff, by specialty)

Patient-side engagement: Segmentation is important. The complexity of disease, condition, PAM (level of activation), supports, etc…

Payer-side engagement

Workflow considerations: Policies should support both synchronous and asynchronous workflows, and the avoidance of adverse events is an important Clinical focus.

Caution: Policy isn’t the main driver for many of these things; TAM (Technology Adoption Model) provides high usability and usefulness

Let the clinical use case “drive” the work, and let the other things (business design, policy design) follow from that

Concerns:

What if patient information (inaccurate, partial) leads to potential adverse events?

Is this a data-entry consequence (regardless of who is entering the data?) Perhaps best addressed using Meta-data (provenance, veracity of info) to provide context

Variation - in source of data (human vs. device) and process of capture and entry;

Is this purposeful inaccurate data different, entered online, vs. face-to-face?

Are there tools to apply to increase detection? [RESEARCH AREAS]

What is the liability, depending on the process (who enters data, who validates)?

TEP agrees that getting high-quality data is the goal

Frequently NLP provides more accurate data than structured data; there will be dynamic evolution of data analysis strategies

Will always need unstructured data

Can describe/predict accuracy based on meta-data, in some ways…

Human Performance (Slide 7)

Patient-directed care: encouraging the patient voice and a means for communication for that voice

Motivation/Incentives: Will there be financial incentives for the consumer? (e.g. PGHD use could see removal of copay (?))

Will there be further incentives for the providers?

Other Incentives include non-financial (e.g. patient direct use of e-tools may save time, increase accuracy, increase value, etc…)

System design that takes into account human performance for high usable and usefulness

Health literacy

Robust understanding of patient preferences & capabilities; Locus of control, health literacy, linguistic literacy, psychosocial support, mobility needs; Critical for all forms of care (real, virtual…); process transparency

Maintain focus on importance of behavioral impacts. But avoid being too specific in this area

Research (slide 9)

Behavioral economics…Important area

Measurement (slide 10)

Will need to elicit high-accuracy information from patients, and compute directly on that data (e.g. the extent to which we make good use of patient time, and team options/actions will be needed)

Next Steps

Ian Hoffberg will update the draft outline of the final report with the TEPs comments on PGHD drivers in the future, and additional work needed.

The next TEP meeting is on October 21 at 12:00pm EST

The meeting adjourned at 1:30pm EST

Meeting Attendees

Name	**Organization**
Michael Barr	American College of Physicians
Donna Cryer	CryerHealth
Mary Jo Deering	ONC
Frank Fortner	Iatric Systems
Robert Jarrin	Qualcomm Life
John Mattison	Kaiser Permanente
Holly Miller	MedAllies
Gene Nelson	Dartmouth Hitchcock
Chuck Parker	Continua Alliance
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP
Jonathan Wald	RTI International
Jim Walker	Siemens

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
October 21, 2013
12:00 pm – 1:30 pm EST

Objective: TEP will review the Phase 2 deliverable outline slides, focusing on the additional work needed section which is a continuation from the last meeting, review the diagram outline of the drivers of PGHD to identify gaps and priorities, and re-affirm the draft outline for the final report.

Meeting Summary

Introduction

Ian Hoffberg conducted roll call. List of attendees included at the end of this document.

Kate Berry provided an overview of the meeting objectives.

Discussion

Jon Wald directed the panel to the last slide (PGHI content) of the phase 2 outline draft slide deck to review areas of attention that we did not get to in our last meeting. What areas need to be developed, considered or explored?

Danny Sands would like some clarification for the group as to the phase 2 deliverable due date? Concerned on how much time we have left to finalize the end report.

Kate Berry stated the goal is to finalize stage 2 deliverable by mid-December. There is the potential for a presentation to the Consumer Empowerment Work Group of the Standards and Policy Committee; we are not sure where that stands.

Virinder Batra would like to see more standardization in the disease management area with a focus on a chronic disease and figure out what the content is. It can take us a long way to getting information from the patients. A very high level example (like diabetes) to give a point of view; data elements that can be standardized; a template of what is required for standardization.

Leslie Kelly Hall suggested that we think of a construct of minimum necessary structure that we need to have. Such as the content for Questionnaires; this is one area that can be put into standards and policy quickly. Or from a standpoint of the top conditions what are the things we need to know from a patient and make sure that structure is in place. Also concerned about the timeline like Danny, what content can we have and meet the deadline?

Gene Nelson thinks that important areas to have standardized content of PGHI are patient reported outcomes, physical health, mental health, social roll, productivity, outcomes that matter to the patient; reflect their changing quality of life outcomes. General measures of patient reported outcomes that could apply to anyone, but also specific conditions (heart failure, joint replacement) need standardiza-

tion. A standard way of asking what an individual's goals or outcomes are (ex: walk up bleachers at the ball park).

Leslie Kelly Hall agrees with Gene's comments. Observations of Daily living (pain, weight), things we would ask in any kind of status question of a patient. Getting the values integrated is important.

Jim Walker thinks that with our timeline it may not be feasible, but would like to extend on what Gene was saying. There is a set of patient preferences and capabilities, preferred communication channels, decision making styles, risk aversion, adherence style, a whole set of things that if we are going to support virtualized care teams providing patient focused care we need a set of things to ask the patient in a validated instrument and then share in a standardized form so everyone will know how the patient wants their stuff.

John Mattison added that there are a series of questions we can take on with our deadline. First how do we manage the trade off of standardization and innovation? What do we know is important and what set of standards is addressing the known important stuff? Where are the areas that we know there is information out there that we want from patients but do not currently have, but is likely to emerge through evidence based medicine and practices based medicine that are increasingly important? After we sort that out what process seem to be aligned and could be standardized now and what areas do we expect need to be re-educated where the existing practices are not the model of what we want to use. If we are going to make a recommendation we may not be as transparent as we want to be. There are areas where for instance psychometric profiling that are unexplored territories. We need to have a better understanding of compliance and option selection. If we make a recommendation then here is what we know and here is a good process but here is what we don't know and we need to be able to reserve the right to identify a process later to standardize in the space as we need to allow for innovation before we can understand how to approach this issue.

The TEP agrees with Johns comments.

Jon Wald summarized Johns' comments as saying that there are areas that are well understood, areas that are partially understood and other areas that are not understood yet. In each of those areas the definition of those areas or standards or important information to convey or communicate in those areas need to be titrated to how much change, or learning, and innovation we expect.

John Mattison added that we should propose an ongoing process of understanding how we know, when we know enough to recognize a specific process or standards body of innovation and how we manage to that evolving level of confidence that we know enough to apply a specific set of standards and processes.

Holt Anderson see's that we are providing a vision of trends to move forward but we are not including who the actors are in each area of anticipated drivers for stimulating and impacting PGHD in the future. For example the technology changes would include certain types of associations, or industry associations. The clinical area would include certain clinical professional associations. Should we be trying to identify at this point?

Danny Sands asked Holt to clarify if he means a 'day in the life' scenario? Or who is going to shape these evolving these standards, processes in the future?

Holt Anderson responded that yes, who is going to buy into it? Who is going to be supporting the certain directions that we go in when we establish a standard, or we suggest a standard needs to be established. Who are the actors who will need to impact that to get it accepted and implemented into practice? And what does that timeline look like? It may be ambitious to put a timeline on it but identifying the crucial actors who need to sign on to a new direction.

Danny Sands expressed concern that with standards we are so early in this space if we move to standardization it may cut off some of the innovation.

Holt Anderson responded that he doesn't want it to be so strict to standards but in the four areas outlined in the stimulating PGHD in the future diagram there are some natural partners, actors, who will have an interest in those specific areas, and should we be identifying them at this point or just let it evolve?

Leslie Kelly Hall thinks it would be great to provide technology standards that can accommodate these high level areas but then let the market evolve.

Jon Wald summarized what Holt was saying that in addition to thinking about the what, we should also start thinking about the how, and who.

Virinder Batra followed up that there will be some early adopters who will be trying this out and the market will end up deciding it in the future.

Benjamin Moulton would like to see more focus on shared decision making. Information can be generated, patients asked of their preferences, patients told of their options, values solicited, that will be a driver for moving this forward.

Jon Wald agrees it will be more explicit on the slides.

Gene Nelson added that under patient activities shared decision making is mentioned.

Benjamin Moulton followed up that the IOM is going to release a report, about 6 states have embedded it, for example in Massachusetts if you want to be an ACO or medical home you have to be certified and assure the state you are following through. It will give meaning to patients, and it will be critical for PGHD.

John Mattison agrees. One thing we need to be careful with is that it is still early in this process and there are unintentional consequences of, for example, Meaningful Use. I think it will be useful for us to be extremely explicit about the need for this data that supports shared decision making, and very cautious about how we prescribe a specific method of doing that. We are going to learn about what matters and what doesn't. We are going to learn even more about how to array the data in ways that support, as suggested, the risk aversion, the compliance patterns, and psycho metric aspects that are quantifiable

which have not been quantified correctly even in the medical literature. As we learn more we will have better ways to support shared decision making. We do need to call it out as being very important, but let's make sure we do not prematurely define what shared decision making should look like.

Leslie Kelly Hall thinks there is a compromise. We want data that will support shared decision making, but we should also have an assumption that the data gets back into the record so it is PGHD. A response to a decision making effort however that is defined, as long as it is reflected in the record with biases, preferences, etc…

Gene Nelson added to the shared that he was recently at a conferences and the theme was the co-production of care by people and patients and healthcare teams for better health and better health care. I am not sure under which trend it would fall under but the notion of co-production, which includes shared decision making. This is a major emerging force that we should recognize and take advantage of.

Jon Wald agrees that it should be added, at least in the medical practice changes, but really the other areas as well.

Gene Nelson added it was a conference that the Johnson Foundation was sponsoring. It was an exchange between the Swedish Rheumatology Quality Registry approach, which goes to shared decision making, and patient reported outcomes and co-production. There is a lot of interest among different stakeholders in the United States (patients, consumer advocates, registry holders, professional organizations).

Jon Wald shifted the discussion of the group to the Measurement slides. There is measurement in a content area, how does a pt measure and share blood pressure, but also measurement in a process area, focused on how do we measure PGHD that is being generated, flowing and being used well or not so well; a process point of view that leads us into meaningful use where ultimately there may be measurement criteria that are applied to objectives.

Virinder Batra stated that there are two or three areas where we can do some measurements. First being how many patients really used it, how many times a year they sent it or the frequency of them sending it that can be input to some sort of patient engagement measurement. Second, is how did it improve the quality, or what kind of data we got was inputted into the EMR, and eventually used in quality measurements to improve the practice numbers in quality. The third thing, how much of the data that was sent was recorded into the patients' EHR. These are measures that can indicate the usefulness of the data for the physician.

MaryAnne Sterling wants us to add patient safety for domains to explore for the PGHI content slide.

Gene Nelson thinks of the opportunities of a framework that can be used is the National Quality Strategy; a three part aim of outcomes, experiences, and affordability/cost. Each of those aspects have important uses of PGHI, meaningful use, and making a difference in outcomes that matter to patients. For example under cost, indirect cost associated for employers measuring presenteeism and absenteeism. Indirect social cost PGHI gets to be very important.

Leslie Kelly Hall mentioned the work being done with NeHC on patients' experience. Two themes are emerging, one is trust and the other is confidence. Having PGHI accepted and used by the provider, will it help increase trust and confidence in one's own health? Is this a way of measuring success?

Jon Wald commented that the idea of technology and all of these areas as building on or strengthening relationships, or in some cases detracting from the strength of those relationships, are really important and would be a great thing to measure and to do that in a consistent way. It is hard but it is important. He wanted to make a comment on Genes earlier comment of sub content areas of important PGHD; it would be nice if there was an organization or place that covered those areas well. Are we looking at pulling a lot of information together to develop a list or are there organizations out there that are doing a good job at aggregating?

Gene Nelson responded that in respect to patient reported outcomes there isn't one specific place. We have been working with the promise investigators; 15 centers and investigator teams around the country being funded by NIH for past ten years to develop patient reported outcome measures for both adults and children that are in the public domain, which have been validated or are in the process of being validated and cover physical, mental role, and many other symptoms for adults and children. Our teams are currently working with promise to go from general measures of health to be more condition specific. Promise is a good repository for measures that can be widely used and can fit in many situations.

TEP asked if we are aware of any of the work being done by the Gordon Moore Foundation funded on PAM and aligning patient care with patient values and preferences. Is Kaiser doing this work?

John Mattison responded that Kaiser is in the process of building a series of collaborations with 3 different institutional pipes. The first is academic research centers, second is care delivery organizations and the third is software vendors. We want to bring together the diversity of talents necessary to really look across data types to discover what's "real". The example I like to use is how many tens of millions of people have been on Metformin and why did it take so many decades to figure out that there is a high prevalence of cognitive impairment associated with the interaction of Metformin and B12 receptors in the terminal ileum; that is something that could have been figured out in a cross data big data analytic environment in minutes using modern visualization tools. We are trying to build that infrastructure (big data analytics and visualization infrastructure across data types), just like other institutions are doing, there are so many examples of what is relevant and what's not relevant that are going to be very surprising that. I am personally approaching it as collaboration on an infrastructure approach rather than a specific research process.

Jonathan Wald asked what extent is Kaiser positioned to share information or to the various projects that are underway.

John Mattison responded that there is some diversity of opinion within Kaiser about how to approach that, but those of you who are aware Chuck Freidman of University of Michigan is pursuing a broad inter-institutional collaboration that I am participating in, sponsored by HHS in Washington DC. There is another model by the editor and chief of JAMIA Lucila Ohno-Machado, the scanner project which I think has merit and value. My personal opinion is that the future belongs to collaboration and collaborators and I am advocating that we contribute our bracket data to organizations trying to overcome the myriad over this data for years. My bias is toward open collaboration model and I think institutionally there is a trend in the right direction. This is my opinion not Kaiser.

Dick Upton added a couple of points. One is integration and also facilitation. Facilitation meaning that it is one thing to have access to the data and another that is a monologue setting; I either input it or I seek it out. One important point is to replace monologues with dialogues. A dialogue is a key toward collaboration, integration, making data available, and PGHD in general. Not only can the patient input data, not only can providers and care givers respond back and forth, but more than responding or more than accessing really being able to have real-time meaningful dialogue.

Danny Sands asked Dick if he means dialogue about the data?

Dick Upton responded that it could be about the data, it could be about questions, it could be about the health. For example HDL puts out a sophisticated report on blood tests, if you have a question it is important to not only have access to the data, and access to the patients inquiry, but to make it meaningful is to have an open dialogue. A need for when a question comes up the patient can get an answer on the data. I feel that the slides seem more like a monologue rather than a meaningful dialogue.

John Mattison agrees, and that there are a lot of startups in this space. First early traction was 'Patients like me' or 'crowd sourced', look at what 'health tap' is doing recently and the volume where they are creating an online real-time dialogue about what this means doctor. Also if you look at what Ronnie Zeiger is doing with his startup, addressing exactly your questions. How we could represent it in this report. Patients have more and more access to their data, the interpretation of that data is subject to confusion, anxiety, and misunderstanding. By supporting a broader dialogue with patients who are now armed with data, and without interpretive skills, it is going to be a critical element of the whole PGHD phenomenon.

Dick Upton responded that being aware of so many startups and so many people trying to invent something new, or reinvent something, there might be a place for when we talk about patient safety, and we talk about trust, and we talk about angst, if there might be a roll within the report to address some recognition of the word or aspect of dialogue with a little bit of guidance. Give some structure and context to the idea of dialogue.

Benjamin Moulton agrees that is the embedded principles of shared decision making.

Dick Upton added that the aspect of real-time is important but doesn't mean I ask it right now. An old ad that I remember is from AMGEN "before we removed the lump in her breast we needed to remove the lump in her throat". I think there are a lot of lumps in throats with people that can only be addressed appropriately by dialogue. It is important that when we speak about data and structure and architecture, and trust and confidence that we talk about accessibility not only to the data but accessibility to a dialogue to a give and take.

Leslie Kelly Hall agrees with Dicks' comments, but would also like to make sure our recommendations includes a structure that promotes access to education and information to explain data that comes from the provider and possibly looks at the use of a taxonomy and a vocabulary for PGHD going back into the record so that we have an opportunity, not just the translation of medicine in the consumer terms, which we do today and pretty well, but for the consumer terms back into medical terms and that will help promote a dialogue. I would also caution us with access, transparency is seeing everything someone's says about you. It is not filtered, it is not dummied down. It is important the access to information is in the raw. We can apply tools, and consumer education, and different kinds of technology that will support learning. I do see some startups coming up with filters that transform the data with no medical review, in an attempt to make it more patient friendly, it can actually re-interpret data. I want to caution against that which gets to the point that dialogue is transparent and shared decision making is really about having all the facts available and access to the information in its purest form.

Danny Sands commented that we have to be very cautious that we are not trying to put too much into this report. All these issues are really important and we need to get to the point of having a finished product. We have to be clear about what is in scope for this report and what should be looked at in future as we move forward.

Leslie Kelly Hall suggested that we have a parking lot area where we encourage further dialogue and discussion for follow on committees or follow on lines of research, but that our focus is really about the most important PGHD getting back into the record, what is that supports shared decision making, that supports only the things that the patient knows like the Observations of Daily living, and really focus in on that. But recognize that there are complex companion and other issues that need to be addressed and name them so they do not get lost for future work.

Danny Sands likes the idea of having a section that talks about all these things in brief, but not necessarily thoroughly and digressing on them.

Dick Upton asked if we should define a scope of interaction. When we talk about the PGHD and all the information we have been dealing with is at least a reference to how much interaction is to be expected, the interaction between the patient and wherever the data resides.

Jon Wald thinks we all agree that the basic components, like what you said Dick, the one way of sharing of information from a patient or sharing information to a patient, the standards, the technologies, the process mechanisms, etc…that supports and allows all that, are ultimately in support of very rich and very meaningful dialogue, understanding, learning, and real progress toward shared goals. It doesn't reduce the need to focus on the components and doesn't suggest that we will ever be done with finding better ways to connect with people trying to make difficult decisions.

Jim Walker added that we should be careful about specifying too much about means. If we develop good measures of patient experience, quality of care, and safety of care, I think we can avoid putting things into micro-specified buckets.

Jonathan Wald likes that comment but worries about how we think about future meaningful use measures. How far away they can get from where they need to be. For instance Virinder commented about measuring three different things. They are measureable, and they are countable. Dick commented that does measuring a number of transactions or how much PGHI gets into the record demonstrate meaningful dialogue? That is not clear, maybe sometimes it does and sometimes it doesn't. The question I am leading up to is how can we be smarter about the measures that we want? We want to get as close as possible to something meaningful and not something that is just easily counted.

Leslie Kelly Hall agrees and added that if we get to transactions that we count we may end up missing the mark. I would rather see us measure something that is more of a motive rather than transactional. We are asking for patient engagement as a result of PGHD, that there is a meaningful dialogue, shared decision making, trust, confidence, I want to see us measure at that level.

Jim Walker agrees with Leslie, if we ask the patient questions did you understand everything discussed they either did or they didn't. If they felt like they were involved in the decision making and production of care? If we ask that kind of thing then we can leave it toward organizations and patients. Different things happen to different patients to answer those questions the same way. That is one answer; try to focus on one high level general characteristics of shared decision making, and feeling included and feeling that your needs have been taken into account.

Ben Moulton doesn't think it is terribly complicated to measure, looking at the policy area slide we have promoting patient and caregiver trust, confidence and promoting provider engagement, promoting the use and shared decision making bridges all of these issues we are talking about and you can measure it with one or two questions. Where you told your options and were your opinion elicited? Did you feel your provider understood your value points?

Neil Wagle is trying to understand how to balance practical considerations of what we can measure vs. we are getting what we want to measure is that people are meaningfully using this data. There is a concern that as we start focusing on whether the patient has really gotten what they want out of it we might lose the patient entered data component of this and it might bleed into all aspects of their relationship with their provider. I know we want to go beyond just the collection of data and presented in the EHR but I do believe that is the first step that is the first set of measures is that. The measure is the percentage of patients PGHD in the EHR. If we are trying and figure out how the data can be more meaningfully used I think the best course would be to pick some areas that are going to be at the front line of PGHD. PHQ2 and PHQ9 (Patient Health Questionnaire) is something that everyone is starting to do for a number of reasons. One example and we can think about these for other categories of the taxonomy, but one example for a PHQ9 level greater than 15, test patient was there a change in the med list, we run into concerns of being so specific we lose flexibility, it is hard to get a general measure of whether the data was meaningfully used.

Virinder Batra added that we could define X amount of jobs, in the sense that, changing up a prescription, there can be a well defined set of jobs that the patient does and to count the jobs the patient has successfully done could be a measure of patient engagement and the percentage of the patients using them.

Michael Lardiere wonders if we are focusing too much on the patient using the data, the patient is sending the data and that is what we want, but we want the provider to use the data not it just being stored in the EHR, but that they are using it. Unless the provider can sees it and can make an evaluation of whatever the data is (PHQ9, heart data, weight, pulse) unless the provider can make some medical judgment about it and say that's good that's bad you need to change this or not change this then it is just data that is floating around and nobody's using it. We should have a measure of jobs that the provider does, or activities that the provider does, after they received the data.

Danny Sands added we are talking about is the impact of the data; the impact could be the patient can take action just because they are seeing the data, consolidated for them, presented to them, and just the fact that they are being measured can impact behavior. So the impact is on the patient side and the provider side.

Dick Upton agrees that it should be both, which coincides with the term dialogue.

Jim Walker thinks that one problem with focusing on provider actions, which may have already been implied, if we do succeed in using business process management systems, and other systems that enable patients to do more self-care with follow up and feedback and enable more standardized tests to be done, not by a human, but a computer system overview. The issue is did the patients information eventuate something appropriate to happening, not specific type of human being doing something.

Jon Wald offered another example to what Jim is saying. If the patient is seen for a visit for a hypertension check and the meds are adjusted that can be due to the lack of useful information that would allow the patient and doctor to decide that we need to stick with the meds as is before we make a change. It cuts both ways, there may be a rich flow of information that leads to an active decision not to take action, and that may be the correct decision and a signal of value.

Benjamin Moulton thinks that is one of the reasons why it is hard to come up with a measure of meaningful interaction with PGHD.

Danny Sands thinks one of the challenges we have is how we have defined PGHD is everything. We could narrowly view it as physiologic data (blood pressure, blood glucose, etc…), but we are including a whole set of things in our definition of PGHD so understanding the impact of it is not easy, but I think we all agree there needs to be able to demonstrate it makes a difference.

Leslie Kelly Hall added that there is work the Glen Elywn (Dartmouth) is doing with identifying levels of engagement, and he talks about five levels; awareness, knowledge, motivation, action taken or behavior change, and sustaining health. Perhaps that helps us in the future by knowing how we increase levels will dramatically show how we improved the interaction engagement of the patient and the provider as well. That can be something in the future.

Danny Sands commented that this is very analogous to the Prochaska's stages of change model.

Leslie Kelly Hall agreed it is very similar. Glen has been looking at a lot of research, may be publishing soon or has already, but he is trying to come up with something that is very representative of all behavior change, is not a proprietary tool. It helps to identify collaboration toward a common goal.

Jon Wald directed the conversation to the final report outline to see if there is any input from the panel on structure, high level changes, etc…?

Danny Sands added that we only have about a month to work on this and get everyone signed off on it so it is important that we do review this outline. We should add a section for other issues to be considered, before the conclusion.

MaryJo has a question about the Practical Guidance section is happy to see it where it is and wants to make sure we are able to apply it to our phase 2 work. We already did a lot of practical guidance around the phase 1 work that was very much appreciated. As speaking for ONC we would like for us to double check our guidance in those areas and see if it needs to be tweaked or expanded or if there is anything additional that needs to be said once we have nailed down the areas we are working on now. It is located in the right position and to assume it will include that. The other question or observation is what we have has small Roman numeral d would become section X (ten), that would be different than practical guidance.

Erin MacKay asked if we have some minor wording suggestions would you like us to pass that along via email? Or cover them now? What's most helpful? Because I think the overall structure looks great.

Jonathan Wald thinks sending them by email would be great, unless it is the quality of understanding through discussion we can discuss otherwise email would be terrific.

Erin MacKay has a question about the marketing with patients found in the appendix, what is the background and thought about phrasing it as outreach and education opposed to marketing.

Jonathan Wald thinks the intended meaning is definitely outreach and education but the phrase of marketing is the idea that patient often times respond strongly to direct suggestion or request at the point of need or point of opportunity. Would you say that fits into outreach and education?

Many panel members agree and would like to see the marketing phrase replaced. Other phrase proposed is outreach for adoption, or spurring adoption. Outreach and education is pretty broad.

Jim Walker recommends that we keep marketing, the statement that was just made about patients having teachable moments is a marketing statement, partly an audience thing, but one of the reasons to think of that is because as clinicians we are prone to focus on the teachable moments when a patient is in our presence or control, there are lots of other teachable moments, for instance when you find out your health insurance deductable will now be two thousand instead of 50 dollars a year. Marketing isn't that bad, it may sound bad to academics.

Leslie Kelly Hall suggested we use the term promotion

Erin MacKay agrees that is a good balance, the consumer community might think we are trying to sell them something.

The panel agrees the promotion is a good phrase to use, encouraging rather than selling.

Gene Nelson thinks the outline is very good; one concern is under particle guidance, members of care team review data to determine relevance (nurses, clinical team member, and physicians); I think the theme here is that the patients are part of the team, under practical guidance we really want patient engagement in the application, in the use and implementation of the PGHD in the clinical settings to have the patients at the table would be a recommendation. Healthcare is a two-way street, and we are trying to maximize the use of PGHD, the patient should be at the design table and part of the education to have a push and pull phenomenon so they understand the value of that use of that data along with the clinical team. It should be two way all the way through.

Jim Walker agrees with Gene and would like to take it another step further. Patient is the core member of the care team, the patient hire and fires the team, modifications here and there, and partly it is in how it reads, but it seems to me if we started by saying Patient is the core of the team and they can be the executive sponsor, general contractor or basically do it themselves with minimal help and say we are going to talk about the care team all the way through here. Any time we talk about provider it is a sign that we have fallen back into the old paradigm, or never gotten out of it. It goes back to the comment, did the provider do something? That is not the question, the question is did the care team together, usually the patient being the starter and affecter get what the patient wanted done. We can look at the whole thing and is the patient at the heart of it, and being the engine of it, and final arbiter of it or is this provider and we are trying to include the patient in a little bit.

Leslie Kelly Hall agrees with Jim and stated that there is no care team when the patient is missing; it is the only team member who has to be there.

Michael Lardiere also agrees, but questions did the patient get what the patient wants done? or did we get good care? I as a patient have no idea what is good care so I don't know if I should be relying on myself to get done what I want done, I really want good care.

Jim Walker would define good care as the patient and usually the physician sat down and talked about the patients' goals and options etc…and agreed upon a plan and then the plan got performed the way the patient thought it looked.

Gene Nelson commented that it may be helpful to have a conceptual model or diagram of people moving in and out of relationships with clinical care teams and how PGHD is flowing forward and is feeding back to enable better care, and better decisions, and better ability to track outcomes to engage patients, etc…a conceptual model would make the points that are being made, that it starts with the person, generally, at home or in the community and they contact a care team or clinical person virtually, or face to face in a variety of ways and locations and the point is over time the patient enjoys the best feasible outcomes that they wish, and best experience of getting care that they could have and that is accomplished at the lowest cost to society. To have some model that sets that up, and shows the data flows to some degree as in part being PGHD might frame the view.

Dick Upton thinks one of the best messaging pieces we have is the phrase a clinical care team, which immediately draws everybody, irrespective of the audience, clinical realities opposed to the business realities are at the focus of so much debate, and likes the approach.

MaryJo does not want us to forget that family caregiver is a key member of the care team

Dick Upton says maybe not, maybe the patients daughter is the key member or the 35 year old smart as a whip lawyer is the patient themselves and is the key member and they just get a little bit of council every once in awhile. Part of the value of team is that it takes into account the reality which is in a given time in life and clinical trajectory, who is the most important and most enduring members may change. Think about how many patients have the same team that had 10 years ago, but they have always had a team throughout that time. People are always coming on and off a team, sometimes, in blinding speed, but the reality is if there is a patient, and as long as they are a patient, they have a team.

Jonathan Wald followed up that there are a lot of shades to this, and are important for us to get right and into the report, and wants to thank everyone for their contributions today.

Kate Berry would like to echo Jons' comment and say thanks, this has been an extremely productive discussion and we will capture the notes and we will continue to work on the outline.

Next Steps

Ian Hoffberg will update the draft outline of the final report with the TEPs comments on PGHD drivers in the future, and additional work needed.

November TEP meeting is cancelled while the final report is being drafted. First draft will be submitted to the TEP before December 6.

The next TEP meeting is on December 9 at 12:00pm EST

The meeting adjourned at 1:30pm EST

Meeting Attendees

Name	Organization
Holt Anderson	NCHICA
Michael Barr	American College of Physicians
Virinder Batra	Intuit
Kate Berry	NeHC
Mary Jo Deering	ONC
Frank Fortner	Iatric Systems
Leslie Kelly Hall	Healthwise
Robert Jarrin	Qualcomm Life
Erin MacKay	National Partnership for Women & Families
John Mattison	Kaiser Permanente
Benjamin Moulton	Harvard School of Public Health
Gene Nelson	Dartmouth Hitchcock
Erin Poetter	HHS
Danny Sands	Society for Participatory Medicine
MaryAnne Sterling	Sterling Health IT
Richard Upton	UPTONGROUP
Neil Wagle	Partners Healthcare
Jonathan Wald	RTI International
Jim Walker	Siemens
Susan Woods	VHA

Attendees not reflected on this list should contact Ian Hoffberg at ihoffberg@nationalehealth.org to amend the list.

Patient Generated Health Data (PGHD) Project
Meeting of the Technical Expert Panel (TEP)
December 9, 2013
12:00 pm – 1:30 pm EST

Patient Generated Health Data (PGHD) Project
Phase 1 Case Studies related to Meaningful Use Stage 3

SGRP 204B

Provide 10% of patients with the ability to submit patient-generated health information to improve performance on high priority health conditions, and/or to improve patient engagement in care (e.g. patient experience, pre-visit information, patient created health goals, shared decision making, advance directives, etc.). This could be accomplished through semi-structured questionnaires, and Eligible Professional (EP) and Eligible Hospital (EH) would choose information that is most relevant for their patients and/or related to high priority health conditions they elect to focus on.

Based upon feedback from HITSC this should be a MENU item in order to create the essential functionality in certified EHRs.

Relevant case studies:

- *Pill Phone Study*
- *Dartmouth-Hitchcock Spine Center*
- *Karolinska University Hospital*
- *Brigham and Women's Hospital*
- *The Group Health*
- *Kaiser Permanente*
- *Mobile Health Project*
- *Veterans Health Administration*
- *Project HealthDesign*
- *Vanderbilt*
- *Partners Healthcare*
- *Agency for Healthcare Research and Quality (AHRQ)*
- *VitalHealth (Emergis, OLVG, GGz Breburg)*
- *NoMoreClipboardsParkviewPhysicians Cardiology Group (PPCG)*

SGRP 204D
Provide patients with the ability to request an amendment to their record online (e.g., offer corrections, additions, or updates to the record) through Virtual Data Tool (VDT) in an obvious manner.

Relevant Case Studies:

- *The Group Health*
- *Kaiser Permanente*
- *Geisinger*
- *Accenture Survey*
- *Veterans Health Administration Loma Linda health Care System (VHALOMA)*

SGRP 207
EP Objective: Use secure electronic messaging to communicate with patients on relevant health information

EP Measure: A secure message was sent using the electronic messaging function of Certified EHR Technology by more than **10** percent of unique patients (or their authorized representatives) seen by the EP during the EHR reporting period.

Relevant Case Studies:

- *Pill Phone Study*
- *The Group Health*
- *Kaiser Permanente*
- *Vanderbilt*
- *Brigham and Women's Hospital*
- *Veterans Health Administration Loma Linda health Care System (VHALOMA)*
- *Penn State*
- *Qualitative Exploration – Doctors who are using email with their patients (phone survey)*

	SGRP 204B	SGRP 204D	SGRP 207
PPS	X		X
Mobile Health Project	X		
Dartmouth	X		
Karolinska / SRQ	X		
Group Health	X	X	X
Project Health Design	X		
Kaiser	X	X	X
VHA	X		
Vanderbilt	X		X
B&W	X		X
Geisinger		X	
Partners Healthcare	X		
Accenture Survey		X	
AHRQ	X		
VHALOMA		X	X
Penn State			X
Phone Survey			X
Doctors using email (survey)			X
VitalHealth	X		
NMC-PPCG	X	X	X

Kaiser Permanente (KP) supports all 3 recommendations of MU III

- KP implemented an EHR system that provides their patients a suite of online patient services. Through the use of secure messaging system they have provided the patient a tool to communicate to the provider their health goals, pre-visit information and other patient experience. The secure e-mail system also enables patients with the ability to amend their medical record online by offering corrections, additions and other updates via the messaging system. The providers are able to communicate with their patients with the support of message templates and prewritten patient education handouts. This fosters shared decision making and being able to communicate with patients on relevant health information.

The Group Health Study (GH) supports all 3 recommendations of MU III

- GH implemented EpicCare, a system-wide Electronic Health Record (EHR) that encompasses
- ambulatory documentation, prescription orders and dispensing history, laboratory/pathology results, radiology, online consultation, mental health records and other additional services. Via MyGroupHealth, a secure web portal, patients are able to submit PGHD and improve patient engagement in care by providing their experiences, pre-visit information, health goals, etc… Patients have access to their medical records and can make corrections, additions and updates to their health record. GH advocates the use of secure messaging system for patients and care providers to communicate and share in decision making rather than having in-person appointments or telephone encounters.

NoMoreClipboards (NMC) Case Study at Parkview Physicians Cardiology Group (PPCG) supports all 3 recommendations of MU III

- NMC implemented a study where the practice conducted baseline lab testing on the patient (in-person consent was obtained). The measures included blood pressure, lipid and BbA1c, online survey (repeated at 6 months and 12 months), Daily health diary in PHR (patients can self-enter and transmit their blood pressure, blood glucose, height, weight and BMI to the practice), and daily reminders to complete and submit their diary information. Personnel from Parkview Research C enter (PRC) helped the patients set up a PHR account and provided training on the use of the PHR. Submission of diary information and all messages are transmitted securely via Med-Web HIE. Patients have reviewed the clinical data imports in to the PHR and have identified errors; they are notifying the practice to correct the data in the EHR. Patients with an ePHR had improved understanding of their conditions and adopted health behaviors. They are more engaged, and more likely to adhere to prescribed therapies and treatment plans, and more likely to enjoy improved outcomes and quality of life.

Pill Phone Study (PPS) supports SGRP 204B and SGRP 207

- PPS this wireless cell phone project enables patients to receive medication dosage reminders, recording dosage records, and access to medication information such as side effects or interactions. Through the Pill Phone patients were able to submit PGHD in hopes to improve medication adherence for their health condition. Via the Pill phone web application nurses could set up reminders for patients and track medication adherence in order to give guidance if necessary.

Mobile Health Project supports SGRP 204B

- This mobile tool collects and transfers PGHD to the care team. The health care professionals are able to monitor the patients' data and intervene early quickly if a patient shows adverse health status. Through the wireless devices and smartphones patients are able to provide important PGHD to improve performance on their health condition.

Dartmouth-Hitchcock Spine Center (Dartmouth) supports SGRP 204B

- The Dartmouth project enables patients to generate a health report prior to the visit with the care provider from home or at the Spine Center. This report will be reviewed by the provider and patient in the visit for shared decision making for plan of care. Access to the data reporting tool allows patients to generate PGHD to improve patient engagement in care.

Koralinska University Hospital and the Swedish Rheumatology Quality Register supports SGRP 204B

- This project is based on a point of care process. The patient records their health status on a computer in the waiting room prior to the visit with the care provider. A summary report is generated that is reviewed by both the patient and provider in the appointment facilitating shared decision making for plan of care and improving patient engagement in their care.

Project HealthDesign supports SGRP 204B

- Project HealthDesign has 5 teams capturing PGHD from patients to be utilized in the clinical practice. The data transmitters ranged from smartphones to household monitors to tablets. The PGHD is transmitted to the care team and then used for care planning to improve performance on health conditions.
    - BreathEasy – RTI International and Virginia Commonwealth University designed an application for patients with asthma to provide a clearer picture of their health in everyday life for treatment and self-monitoring.
    - Chronology.MD – University of California, Berkeley, in partnership with Healthy Communities Foundation and University of California, San Francisco, helped young adults with Crohn's disease create visual narratives of their condition and treatment to provide concrete feedback to providers about how they feel from day to day.
    - dwellSense (formerly Embedded Assessment) – Carnegie Mellon University developed and evaluated sensor technologies that monitors the routines of elders who were at risk for cognitive decline, providing data for long-term functional assessment and treatment.
    - Estrellita (formerly FitBaby) – University of California, Irvine collected ODL information from high-risk infants and their primary caregivers to allow them to more easily interface with their health care providers to improve care and communication.
    - iN Touch – San Francisco State University worked with low-income teens who were obese to see whether and how tracking ODLs would inform the participants' health management and well-being.

Veterans Health Administration (VHA) supports SGRP 204B

- The VHA initiated a home care program called The Care Coordination / Home Telehealth (CCHT) to provide managed care for patients with chronic health issues. Utilizing biometric monitors and messaging devices to communicate and monitor PGHD the CCHT is able to improve performance on high priority health conditions.

Vanderbilt University Medical Center (VUMC) supports SGRP 204B and SGRP 207

- VUMC initiated the MyHealthAtVanderbilt (MHAV) program to allow patients secure messaging with their providers and to view basic health information in the electronic health record (EHR). Access to the EHR would be in-person and with restrictions. Sensitive data would require a health care provider to interpret sensitive information. The secure messaging aspect of this project allows the patient and provider to communicate on relevant health information and shared decision making.

Brigham and Women's Hospital (B&W) supports SGRP 204B and SGRP 207

- B&W initiated an eJournal project that engages patient-provider communications and information collaboration. Patients would submit their eJournal prior to a scheduled visit with their care provider. They would answer questions designated to specific modules. Providers were encouraged to use a suite of tools to respond to the eJournal submissions and to update the patient EHR to record the updates found in the eJournal. The eJournal allows the patient to provide patient generated health information to improve patient engagement in care, patient experience, pre-visit information, patient created health goals. The tools available to the provider allow for communication with the patient to foster shared decision making.

Geisinger supports SGRP 204D

- Geisinger Pilot was to assess responses to the need for patient engagement in efforts to improve data quality in EHR's, identify shortcomings in current practices, recommend responsive action, and provide outpatients the ability to request updates to their record online (e.g., offer corrections, additions, or updates to the record) for medications through VDT using structured forms. The patient portal survey support allergies, immunization and demographic data elements. Other promising areas for patient sourced data are smoking status, advance directives, and family health history. Examples of EHR corrections are requesting an old medication to be removed from the active medication list, addition of a new over-the-counter medication, correction of birth date, and addition of family history of a chronic condition. Corrections are submitted online to clinicians.

Partners supports SGRP 204B

- Partners Patient Reported Outcomes (PRO) project is to use PRO to improve the care of individual patients through better monitoring and improved responsiveness. Utilizing structured questionnaire the patient is asked to complete prior to the office visit via an ipad or pre-follow up encounters remotely using a patient portal or phone call with automated answering service or live operator. The questionnaire is made up of mental health questions like mood and ability to think. ADL's type questions cover functional aspects such as walking, climbing stairs, carrying groceries or moving a chair. Patients are asked to rate fatigue, pain, also how often they have had chest pain or pressure when exercising or shortness of breath when sitting or resting.

Accenture Survey supports SGRP 204D

- 500 physicians were surveyed on Patient access to electronic health records.
    - 82% want patients to actively participate in their own healthcare by updating their EHR.
    - A third of those physicians (31%) believe the patient should have access to their full health record.

- The majority of US doctors believe that patients should be able to update their health record including
    - Demographics (95%)
    - Family medical history (88%)
    - Medications (86%)
    - Allergies (85%)
    - New symptoms, self-measured metrics, including blood pressure and glucose levels (81%)
    - Nearly half of US doctors believe patients should not be able to update their lab test results (47%)

Agency for Healthcare Research and Quality (AHRQ) supports SGRP 204B

- The AHRQ use of telemedicine system to self-reported blood pressure and other health data remotely seems to help patients improve their blood pressure and make positive lifestyle changes. The study included two groups, the first group received standard care, while the second group was trained to monitor their blood pressure at home using a cuff, and report those findings, as well as heart rate, weight, daily steps taken and tobacco use. Participants submitted the data to their physicians via telephone or internet twice a week and received information and guidance in return to help them manage their blood pressure.

Veterans Health Administration Loma Linda Health System (VHALOMA) supports SGRP 204B

- The VA Loma Linda Health Care System Portal Mail system clinician-patient agreement was developed and based on guidelines from the American Medical Informatics Association (AMIA). The Portal Mail would be processed by the clinical team and messages would be categorized by type (medication refill, demographics, appointments, co-pay status, and periodic healthcare reminders)

Penn State Milton S. Hershey Medical Center supports SGRP 207

- Penn State initiated a pilot to enhance doctor-patient communication using email. This study consisted of two groups, a control and an e-mail group. E-mail communication was found to be a more convenient form of communication. The purpose of the e-mails was primarily for prescription refills, non-urgent consultations, and to obtain laboratory test results. Rapid, inexpensive, simple, convenient, and asynchronous communication are distinct benefits that could result in a reduction in the number of non-urgent telephone calls to the office, and increase in patient participation in medical decision-making, and an improved linkage to patient education materials.

Qualitative Exploration Doctors Who Are Using E-mail with Their Patients (phone survey) supports SGRP 207

- In-depth phone interview of 45 physicians to survey physicians currently using e-mail with their patients daily to understand their experiences. Four main domains reviewed are e-mail access and content, effects of e-mail on the doctor-patient relationship, managing clinical issues by e-mail and integrating e-mail into office processes. E-mail communication enhances chronic-disease management. Many physicians also reported improved continuity of care and increased flexibility in responding to non-urgent issues. Physicians see a benefit to using e-mail in specific situations with specific patients. Physicians reported better and more-consistent communication with patients who have chronic diseases and require frequent, small changes in management. Several other benefits include continuity of communication with patients (particularly patients who travel), ability to respond to urgent issues on their own time, avoidance of phone tag with

patients, and improved efficiency in certain scenarios. Drug refill requests and dissemination of educational information, including links to reliable internet sources, were also cited as examples of the effective use of e-mail with patients. Barriers identified are difficulty incorporating e-mail into daily office work flow, generating timely responses, inappropriate or urgent content in the messages, confidentiality issues, and lack of reimbursement for this service.

VitalHealth (Emergis, OLVG, GGz Breburg) supports SGRP 204B

- International case studies at Emergis mental health care institution in Holland, the Onze Lieve Vrouwe Gasthuis (OLVG) in Amsterdam, and GGz Breburg in the Netherlands. VitalHealth is a web-based solutions provider for health management. Their software application Questlink provides PROM's (Patient Reported Outcome Measures) questionnaires for Routine Outcome Monitoring (ROM). The EHR provides a separate tab for all of the ROM results to be entered, and viewed in the system via QuestManager.

Patient Generated Health Data (PGHD) Project
PGHD Examples Submitted by TEP members

- *Submitted by Robert Jarrin*
  - *Pillphone Case Study. August 2010*
    - http://www.qualcomm.com/media/documents/wireless-reach-case-study-united-states-pill-phone-english
    - http://mobihealthnews.com/10196/mixed-but-encouraging-results-for-medicaid-patients-using-pill-phone-app/ , Feb 9, 2011

- *Submitted by Mary Jo Deering*
  - *Patient-Generated Health Data: White Paper. April 2012*
    - http://www.nationalehealth.org/ckfinder/userfiles/files/PGHD%20White%20Paper_April%202012.pdf
    - http://www.nationalehealth.org/ckfinder/userfiles/files/PGD%20Hearing_08_Jun_12%20summary.pdf

- *Submitted by Eugene Nelson*
  - *Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Study from Dartmouth, Karolinska and Group Health. June 2012*
    - http://tdi.dartmouth.edu/images/uploads/tdi_tr_pri_ia_sm.pdf

- *Submitted by Pamela Cipriano*
  - *Alliance for Health Reform Briefing*
    - http://www.allhealth.org/briefing_detail.asp?bi=257
    - http://www.projecthealthdesign.org/media/file/ProjectHealthDesign-Report-Early-Findings-and-Challenges-102011-webres.pdf

- *Submitted by Leslie Kelly Hall*
  - *The future state of clinical data capture and documentation: a report from AMIA's 2011 Policy Meeting. September 8, 2012*
    - http://jamia.bmj.com/content/20/1/134.full.html#ref-list-1
  - *Sujansky & Associates LLC: A Standards-Based Model for the Sharing of Patient-Generated Health Information with Electronic Health Records (July 18, 2013)*
    - http://www.nationalehealth.org/ckfinder/userfiles/files/Standard%20Model%20For%20Collecting%20And%20Reporting%20PGHI_Sujansky.pdf

- *Submitted by Eugene Nelson*
  - *Public-Private Partnership Program, PPP Advisor Volume 2 – e issue 1 winter 2012:*
  - *The Mobile Health Project enhances the care of patients with heart failure. December 2011*
    - http://ppp.od.nih.gov/pppinfo/docs/PPP_Newsletter_Winter%202012.pdf
- *Submitted by Neil Wagle*
  - *Partners Healthcare: Patient Reported Outcomes, Use Cases. February 2013*
    - http://www.nationalehealth.org/ckfinder/userfiles/files/Partners%20Case%20Study%281%29.pdf

- *Submitted by Jim Walker*
  - *Patient Engagement at Geisinger. February 2013*
    - http://www.nationalehealth.org/ckfinder/userfiles/files/Patient%20Engagement%20At%20Geisinger%20Case%20Study.pdf
- *Submitted by Jeff Donnell*
  - *NoMoreClipboards Case Study: An HIE-Populated Personal Health Record for Cardiac Revascularization Patients; 2013*
    - http://www.nationalehealth.org/ckfinder/userfiles/files/NoMoreClipboards%20Case%20Study_An%20HIE-populated%20personal%20health%20record%20for%20cardiac%20revascularization%20patients.pdf
  - *NoMoreClipboards Case Study: Identification, Authentication and Matching to Support Consumer Access to HIE Data; 2013*
  - http://www.nationalehealth.org/ckfinder/userfiles/files/NoMoreClipboards%20Case%20Study_Identification%2C%20authentication%20and%20matching%20to%20support%20consumer%20access%20to%20HIE%20data.pdf

Public-Private Partnership (PPP) Program

http://ppp.od.nih.gov/pppinfo/docs/PPP_Newsletter_Winter%202012.pdf

- **mHealth Summit**
  - Designing an mHealth tool (not limited to)
    - Assessment of health issue
    - Diagnosis
    - Treatment
    - Epidemiology
    - Surveillance, continued care

The Mobile Health Project Enhances the Care of Patients with Heart Failure

http://ppp.od.nih.gov/pppinfo/docs/PPP_Newsletter_Winter%202012.pdf
Improving communication with patients along with coordinated care upon discharge there is a greater probability that there will be a reduced rate of readmission. 3G Mobile tools will collect and transfer critical patient data such as weight, blood pressure and heart rate to nursing staff. The daily exchange of information will enable health care professionals to detect a decline in a patient's health status early and intervene rapidly, helping to reduce unnecessary travel, physician office visits, costs and readmission to a hospital.

MEDICATION ADHERENCE AND mHEALTH: THE GEORGE WASHINGTON UNIVERSITY (GWU) AND WIRELESS REACH PILL PHONE STUDY (PPS)

http://www.qualcomm.com/media/documents/wireless-reach-case-study-united-states-pill-phone-english
The PPS and GWU conducted this study "to determine if the Pill Phone™ mobile application can improve medication adherence" in urban, underserved hypertensive populations and consequently improve health outcomes. The purpose of this study is to measure how 3G technology can help address this critical health problem.

This study was conducted with 3 main goals in mind. The first was to get treated patients to "achieve blood pressure control below 140/90 mm Hg". The Second was to reduce the hypertension and morbidity and mortality rates in urban underserved populations. Lastly it was to increase the medication adherence of this same population.

"The patients in the Wireless Reach Pill Phone study showed a high level of acceptance and sustained use of the Pill Phone application. A survey following the pilot indicated that participants were generally satisfied with the medication reminder software. There was a trend toward increased prescription refill rates with the use of the Pill Phone application and a decrease after the application was discontinued. Larger studies with longer follow up periods are needed to see if similar mHealth systems improve health outcomes and are cost-effective."

- PPS (Key issues, lessons learned, challenges)
  - Low health literacy rate
  - Underprivileged population
  - Non-adherent to medications by self-report
  - Cost affective
  - Ease of use

Results

http://mobihealthnews.com/10196/mixed-but-encouraging-results-for-medicaid-patients-using-pill-phone-app/
The overall results of this seven month study had mixed results. The participants reported that the app was easy to use and was most effective with reminding the patients to take their first daily medication dose but easy to forget to take the later dosages. It also showed measurable results in relation to controlling blood pressure. Adherence to medication, based on prescription refill rates, increased in early stages of the project to 60% but dropped at the end of the study to under 55%. The study did not show any change in Emergency Room visits.

The Pill Phone Study and the Mobile Health Project are Real World examples of how a Mobile Application addresses questions asked in the NeHC Stakeholder Survey.

- 86% of stakeholders said it is either Important or Very Important that the patient/caregiver manages health through the use of electronic home monitoring devices, health-related Smartphone apps or online tools.
- 56.1% of respondents said it is either Important or Very Important to have patient-reported online blood pressure records for their organizations efforts to improve care.
- 52.3% of respondents said it is either Important or Very Important to have patient weight records reported from wireless scale for their organizations efforts to improve care.

Using Patient-Reported Information to Improve Health Outcomes and Health Care Value: Case Studies from Dartmouth, Karolinska and Group Health. http://tdi.dartmouth.edu/images/uploads/tdi_tr_pri_ia_sm.pdf

The case studies done at the Dartmouth-Hitchcock Spine Center, the Karolinska University Hospital and Group Health Cooperative are real life examples of PGHD using health information technologies. "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."

"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 measurements systems in typical clinical settings, and
c. discuss lessons learned on patient-reported measurement systems based on these case studies."

"The utility and feasibility of using-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 principle including:

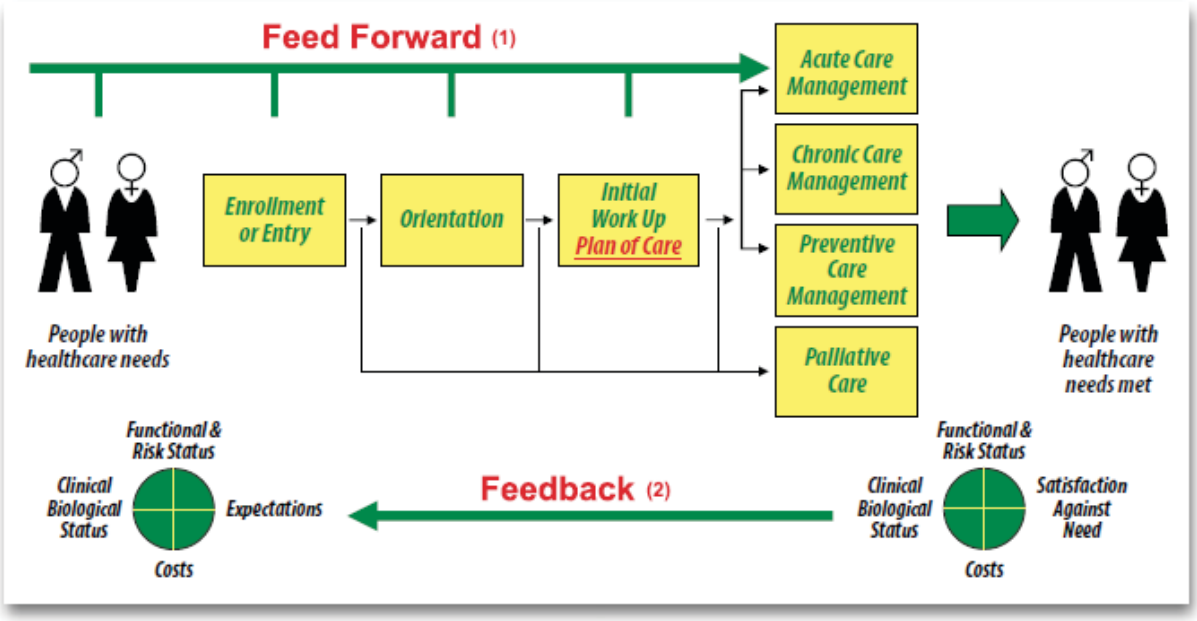
a. Fitting the patient-reported measures into the flow of care and using the data to make it easier for clinician as to do their jobs and for the patients to engage in self-management, make informed decisions, and draw attention to the outcomes they value most,
b. co-designing the patient-reported measurement 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 in users' experiences and new technology"

"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."

"Figure 1 provides a schematic illustrating the use of patent-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 EMR systems)."

FIGURE 1



Feed Forward and Feedbaok 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.

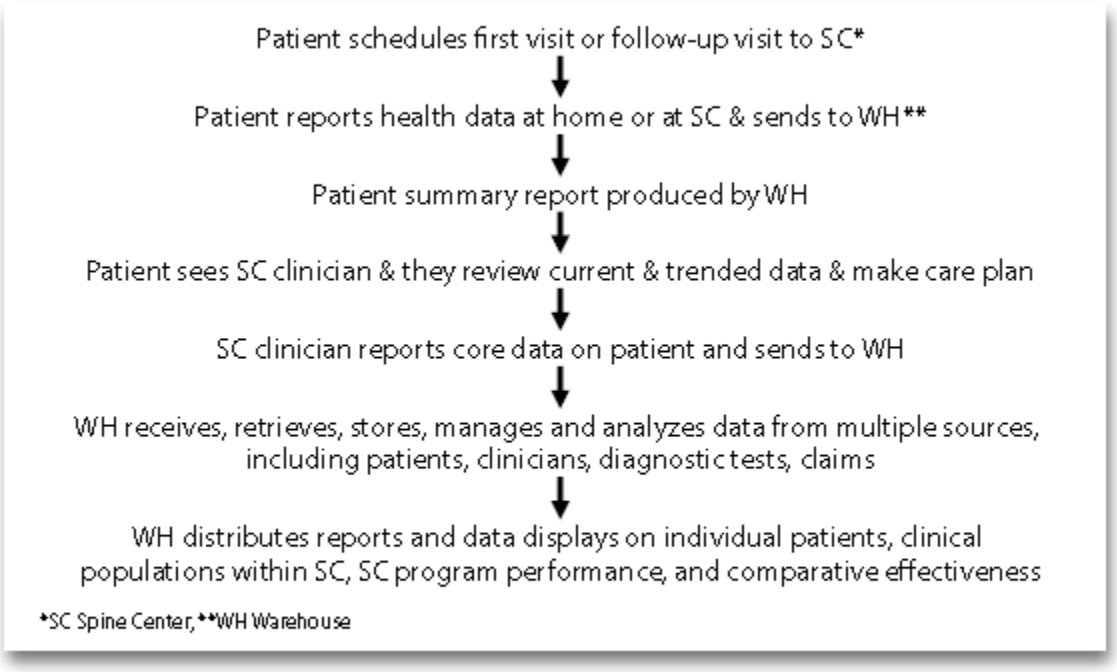
Case Study Number 1: The Dartmouth-Hitchcock Spine Center

The "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."

Flow Chart – Data collected in the Spine Center and its usage:

FIGURE 2



Flow of Data in Spine Center and Data Warehouse

Feed Forward

"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."

Feedback

With each appointment the patient has at the Spine Center the patient will repeat the process of completing the assessment prior to seeing the healthcare provider. The provider is responsible for updating the core registry data. This ongoing process provides the desired longitudinal measures of change in health outcomes. From this information a patient summary report is created and used by both the patient and provider to make any changes to the treatment plan.

Data Trust, Warehousing and Managing Privacy and Security

"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 analyst's 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."

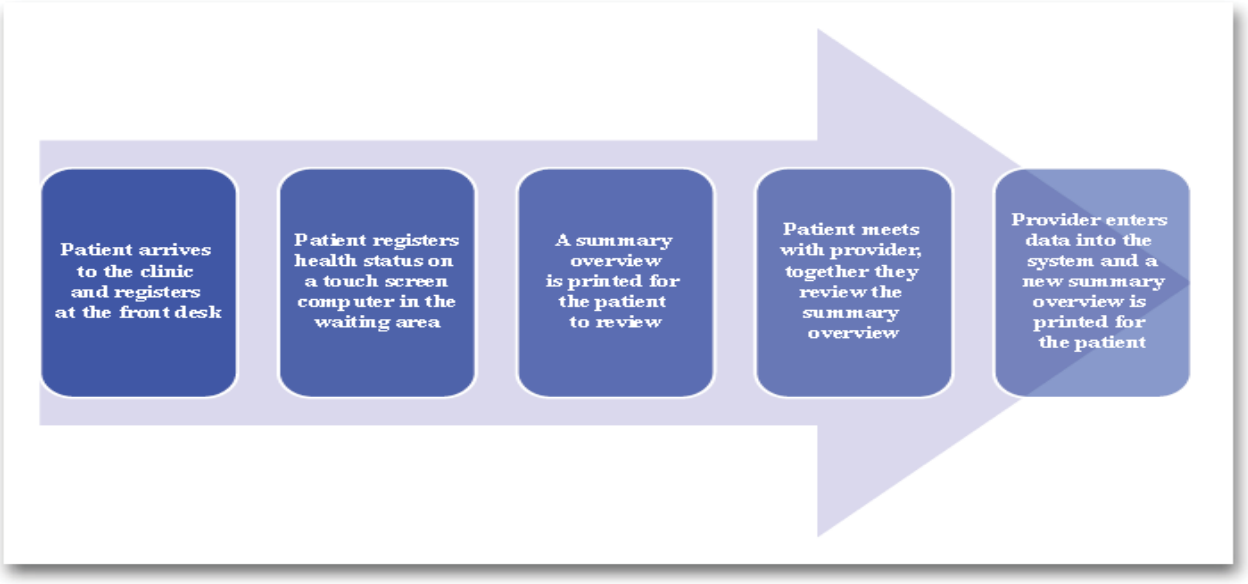
"All patient-clinician electronic communications occur within a secure patient portal to ensure compliance with HIPAA security protocols…the health survey access will only occur via a password protected sign-in for data collection and encrypted data transmission"…informed consent is obtained on all participating patients prior to gaining access 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."

Case Study Number 2: Koralinska University Hospital and the Swedish Rheumatology Quality Register (SRQ)

"The SRQ registry is a longitudinal database that follows patient outcomes over time…The web-enabled SRQ registry makes use of real-time, standardized data provided by patients, clinicians and diagnostic tests to improved 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."

Feed Forward

FIGURE 11



The Feed Forward Process at a Rheumatology Clinic

Feedback

The patient will repeat the process with each subsequent visit. There are multiple levels of feedback from the SRQ:

- Patient Level – “effects of treatment outcomes can be evaluated and each provider can analyze their respective patient group to prioritize work.”
- Clinical Level – “the patient panel progress can be followed along with medication trends.”
- National Level – “benchmarking is made possible by comparison of data.”

Data Trust, Warehousing and Managing Privacy and Security

“All rheumatology clinics own the data they provide to the SRQ registry…only the clinic itself can view its own results and compare is 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. All data and communications with 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.”

Case Study Number 3: The Group Health Case Study of an Electronic Health Risk Assessment Tool

“This case study describes the development and use of an electronic Health Risk Assessment (e-HRA)… integrated with an electronic health record (EHR). 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 EHR. Aggregate data are also used by purchasers and the health plan for population health improvement planning. 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. Physicians and health care providers have an important role in prompting patients to change risky health behaviors. 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 EHR 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 deed recommendations immediately back to them through the web portal and to their clinical teams through the EHR.”

“Through the patient’s EHR portal the e-HRA was designed as a short survey. Patients can take the survey as often as they like and at any time. “Clinical practices are guided to prompt their care teams to complete the questionnaire as part of the 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 update of health risk assessments.”

As stated in this case study the e-HRA has multiple purposes directed at four audiences:

1. Patients
    - Promote patient engagement
    - Activation in preventive care
    - Chronic illness care
    - Providing immediate actionable information upon questionnaire completion
    - Identify health risks
    - Recommendations for primary, secondary, and tertiary prevention
    - Prioritization of prevention activities
    - Provides health resources and health promotion programs
    - Direct entry into EHR
    - Promote patient-clinician relationship based on mutual knowledge and understanding.
2. Physicians & Care Teams
    - Decision support tool
    - Identify prevention and chronic-care needs
    - Delivers actionable information to care teams.
    - Future disease risk estimates
    - Health History taking tool and expedites the systematic identification of a broad range of unmet needs.
    - Reduce history taking burden
    - Increase time efficiency
    - Addresses the hard to ask questions about sensitive issues (alcohol use, substance abuse, and risky sexual practices)
    - Identification of issues that need urgent attention.
3. Employer & Government Health Care Purchasers
    - Population-based estimates of disease risk, health status and health care delivery gaps
    - Assists employers in the design of their wellness programs, prevention benefits and workplace redesign.
    - Performance assessment – allows employers to see the quality of service delivery provided by Group Health providers, provider groups or health plans.
    - Key population-based information on the health-related productivity of their workforce.
4. Health Care Leaders & Managers
    - Fine tuning resource allocation across populations, service areas and clinics
    - Stratifying the population for outreach by clinicians, care management programs and wellness programs.
    - Document the variability in the provision of prevention and chronic illness care across clinical populations to enable quality improvement activities.

Feed Forward

Patients: Once the questionnaire is completed a customized report is instantly provided to the patient. The report is based on three main areas of interest, risk factors, health history and willingness to change. It also provides guidance as to when and how to seek care from their care team, and prompts the patients to make needed appointments. The report also provides links to other information resources, wellness programs, and health coaches, depending on the needs identified. In order to track a patient's progress over time all previous reports are securely archived on the web.

Providers: Summary reports, free text and structured data are transmitted to the EHR. When the patient completes a questionnaire a customized summary report is immediately provided to the primary care team. This report is similar to the patient summary but it also includes care gaps. The report is summarized in a manner that is cognitively accommodating to the physician. "The report becomes its own electronic health record "encounter" that tracks pertinent positives and negatives, and suggests clinical actions. Selected data points are migrates directly to the electronic health record fields. Where urgent concerns are identified, the health profile triggers an in-basket message to alert the clinical team or health plan care management team."

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…for data collection and transmission. To support interoperability, the e-HRA and the Epic EHR data are passed through a secure XML interface."

Patient Reported Measurement Systems:

"All three patient-reported measurement systems…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
- data sets for retrospective and prospective research"

Challenges & Resolutions

- "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.
    - "Setting the expectation that the patient-reported data is needed as a precondition for a clinic visit has promoted participation at Dartmouth and Karolinska"
    - Financial Incentives

- Clinicians must place the patient-reported measurement system results within the context of the patient's current clinical state, prognosis, attitudes and preferences.
    - "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."

- Decision support resources maybe required, including clinical practice guidelines and care protocols, to guide care in such instances as severe depression.
    - "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."
- Resistance during the start-up period. Patients maybe resistant to change and administrators may underestimate how much effort is required to make this type of change initiative successful (Organizational Support). Patients and clinicians will learn how to work together to make best use of the new information stream."
    - "Collaboration with key stakeholders, (such as employers, purchasers, researchers, patient advocates) can enhance adoption and use."

CONTENT

- An ideal health assessment (HA) provides patients with a comprehensive report that summarizes their health status, their care needs and gaps in care.
- It is easy to overburden respondents: use principles to prevent this.
- Items should have a clear purpose and be user friendly, salient to patients and care teams, and actionable.
- Items should be brief, valid, reliable and sensitive to change.
- 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.
- Health literacy varies; therefore it is best to use plain language and to organize information so that the most

ADOPTION

- 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.
- Low response rates compromise the utility of HAs, particularly for those who are at high risk and may be less likely to participate.
- Financial incentives, particularly cost sharing differentials, have promoted HA participation at Group Health.
- Setting the expectation that patient-reported data is needed as a precondition for a clinic visit has promoted participation at Dartmouth-Hitchcock and Karolinska.
- Collaboration with key stakeholders, (such as employers, purchasers, researchers, patient advocates) can enhance adoption and use.

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.

Design and Implementation Principles

The Guiding Principles of the patient-reported measurement system featured in these case studies as stated.

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 the other key stakeholders such as the larger health system, payers, employers, accreditors, collaborative improvement networks and research collaborators (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
    - Consider of these principles in designing and implementing patient-reported data can lead to broader dissemination and more effective use

The Dartmouth Institute provided 3 case studies examples of how Patient Generated Health Data is being utilized in the Real World. These three examples directly correlate with questions addressed in the NeHC Stakeholder Survey.

- Dartmouth & Karolinska
    - 94.4 % of stakeholders said that it is Important or Very Important that the Patient/ Caregiver communicates electronically with provider about changes in health status or adherence to treatment plan electronically.

    - 84% of stakeholders stated that in terms of patient engagement with Health IT it's Important or Very Important that the Patient/caregiver records and updates personal health data online.

    - 60.5% of stakeholders stated that the biggest challenge in integrating electronic patient-generated health data is adapting workflow to accommodate review and potential action.

- Group Health
    - 91 % of stakeholders said that in terms of patient engagement with Health IT it's Important or Very Important that the Patient/Caregiver uses electronic education materials and/or online resources to learn about better health or their own loved ones health condition.

    - 85.5 % of stakeholders stated that in terms of patient engagement with Health IT it's Important or Very Important that the Patient/caregiver uses electronic educational material or online resources to find an appropriate provider.

    - 81% said that in terms of patient engagement with Health IT it's Important or Very Important that the Patient/caregiver uses electronic educational material or online resources to review provider ratings.

    - 62.4% of the stakeholders said it is Important or Very Important for their organization to improve care by having patients complete a Medical History questionnaire online.
        - 15.9% of stakeholders currently have integrated an online questionnaire

    -

- 55.8% of stakeholders rated the level of importance as High or Very High to their organization to encourage patient use of wellness management tools.

- 69.7% of stakeholders currently have or within the next three years to integrate patient generated health data into electronic records.

Alliance for Health Reform Briefing - A Different Way of Thinking About Health Information http://www.allhealth.org/briefing_detail.asp?bi=257

"Panelists discussed innovative Project HealthDesign apps for smartphone-based patient-generated health data, presented findings from smartphone app field testing, identified legal and policy issues faced by Project HealthDesign grantees, and emphasized patient centered data initiatives."

- "Stephen Downs presented an overview of the national Project HealthDesign program. The program seeks to address whether access to granular patient generated health data can make a difference in care. Downs classified this data as observations of daily living (ODLs), which include mood, sleep, diet, medication adherence, etc. Project HealthDesign has helped study participants identify, capture, store and review ODL data and provide feedback to patients after the data is analyzed and interpreted…Downs believes these programs will be effective because of the direct feedback patients receive from providers."

Five grantee teams are working with a variety of patient populations and technologies—including mobile devices and sensors—to explore how ODL data can be efficiently captured and then used in clinical practice.

Team Name	BreathEasy	Crohnology.MD	dwellSense	Estrellita	iN Touch
Project Overview	Working with patients who have asthma to capture ODLs such as use of controller and rescue medications and symptom levels	Tracking ODLs related to daily life with Crohn's disease, including data about mood, weight loss and abdominal pain	Monitoring how elders complete routine tasks such as taking medications, talking on the phone and making coffee	Working with high-risk infants and their caregivers to collect ODLs related to both the infants' and the caregivers' day-to-day physical and emotional health	Monitoring ODLs such as amount of exercise, mood, food intake and socializing for obese teenagers
Devices Given to Patients	Smartphone	iPad	Household sensors	Smartphone	iPod Touch
Partner Institutions	RTI International, Virginia Commonwealth University	University of California at Berkeley, Healthy Communities Foundation, University of California at San Francisco	Carnegie Mellon University	University of California at Irvine	San Francisco State University

- "Stephen Rothemich, MD, discussed BreathEasy, a smartphone PHR for asthma patients. ODL data is entered through the app and viewed by clinicians through the BreathEasy Clinician Dashboard. A user centered design process was used in app development and followed by a 6 month field testing period. Dr. Rothemich stated the impact of BreathEasy was educational for patient participants, who found the app easy to use and enjoyed collecting ODLs, and understood their asthma control and triggers better. The impact of BreathEasy was not overwhelming for clinicians and provided clinically useful information."

    - 86% of stakeholders said it is either Important or Very Important that the patient/ caregiver manages health through the use of electronic home monitoring devices, health-related Smartphone apps or online tools.

    - 59.6% of respondents to the stakeholder survey currently deliver, or are planning to deliver in the next year, information electronically to patients.

    The stakeholders were asked to what extent are the following types of electronic patient-generated data important in your organizations efforts to improve care. The responses indicating Important and Very Important are:

    - 47.3% - Online journal for nutrition
    - 39.3% - Online journal for mood
    - 44.2% - Online journal for fitness

- "Joy Pritts talked about patient generated data. Pritts emphasized the importance of placing patients at the center of care, to ensure engagement and better health outcomes. She identified HHS patient-centered initiatives, including Text4Health, the CLIA program and HIPAA privacy rule, and Meaningful Use. ONC's consumer engagement strategy is the 3 A's: Access, Attitude and Action, which strives to make access to personal health information easier while supporting a shift in attitude about the roles of patients and providers in care, to catalyze the development of tools and services that help consumers take action with the health information. Pritts highlighted ONC's mHealth privacy and security research on consumer attitudes, which seeks to identify consumer attitudes and preferences and explore potential safeguards."

    - Alliance for Health Reform Briefing (Key issues, lessons learned, challenges)
        - Data classified as Observations of Daily Living (ODL)
            - Mood
            - Sleep
            - Diet
            - Medication Adherence, etc…
        - Easy to use applications
        - Patient education on condition and triggers.
        - Cost affective
        - Application was not overbearing on Clinicians or Respondents.
        - Place patient at center of care to facilitate engagement.
        - 3 A's
            - Access – make it easy to access PHI

- Attitude – redefine the role of patient and providers in care
- Action - development of tools and services that help consumers take action with the health information

Results

http://www.projecthealthdesign.org/media/file/ProjectHealthDesign-Report-Early-Findings-and-Challenges-102011-webres.pdf

Project HealthDesign has some early indicators to report with their suite of projects:

- "Chronically ill patients are eager to try technologies that help them take charge of their health."
- "Each patient is different, so personal health applications need to be customizable"
- "New clinical workflows are needed in order to incorporate ODL's into clinical practice"
- "Reviewing ODL data can highlight day-to-day variation for patients and clinicians"

ProjectHealth has also identified some challenges that still need to be overcome:

- Storing ODL Data
  - "Systems that lack sufficient flexibility to handle personalized ODL data"
  - "Incorporating of patient-sourced data into EHR's and clinical data workflows"

- Privacy & Security
  - "Patients participating in several of the projects seem less concerned about protecting their health data; in some cases they have even removed privacy safe guards such as mobile device passwords."

Patient-Generated Health Data White Paper

http://www.nationalehealth.org/ckfinder/userfiles/files/PGHD%20White%20Paper_April%202012.pdf
http://www.nationalehealth.org/ckfinder/userfiles/files/PGD%20Hearing_08_Jun_12%20summary.pdf

With PGHD still in its early stages there are some real life examples of how some of the issues are being resolved and how the boulders facing the PGHD workflow are being met. The following examples from Kaiser Permanente (KP), Veterans Health Administration (VHA), Vanderbilt University Medical Center (VUMC) and Brigham and Women's Hospital show how such issues as Patient/Provider engagement, how to manage large amounts of data and the legal issues related to validation, privacy and security, health-care provider workload, and how to better facilitate the patient-provider communication and information sharing are being addressed.

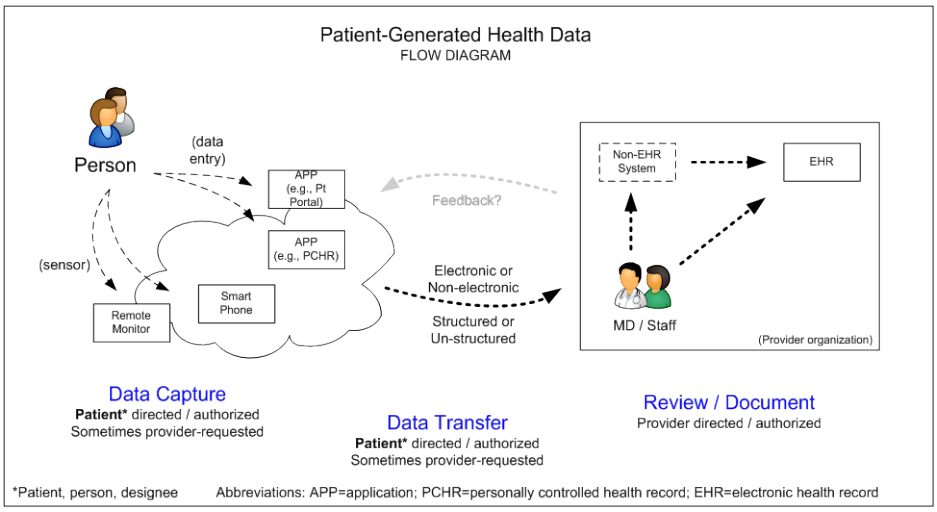
Patient-Generated Health Data (PGHD) are health-related data created, recorded, gathered, or inferred by or from patients, their care partners or those who assist them to help address a health concern. PGHD complement provider-directed capture and flow of health-related data across the health care system.

PGHD Facts:

- We are in the midst of a culture change.
- Significant educational reform will be required to raise citizens who grow up learning to be responsible health consumers.
- Patients want help in quality measures and standards to be able to help themselves and not require physician intervention for everything. PGHD can be considered longitudinal and not just episodic care, where one can be proactive rather than reactive.
- PGHD involves an expanded care team.

PGHD differ from data generated in clinical settings and through encounters with providers:

- Patients, not providers, are responsible for capturing or recording these data.
- Patients direct the sharing or distributing of these data to health care providers.



Examples:

- General data types—health history, symptoms, biometric data, treatment history, lifestyle choices, etc.
- Data-specific examples—blood pressure, asthma inhaler, glucose levels, oral anticoagulant levels
- Drivers to expanded use— advances in data-driven medical science, EHRs, sensors, mobile technology

Note: PGHD data capture/transfers are not limited to certain technology methods. Data capture can be manual and transfer can be by phone or secure messaging.
Kaiser Permanente (KP) - Implemented a suite of online patient-services, in which patients enroll to use secure e-mail. The initial boulder to overcome in this example was the patient and provider engagement with their EHR systems. To overcome this obstacle the promotion of a secure messaging system, secure e-mail, was critical in alleviating the concerns of both patient and provider. "Also, providers were given communication training specific to the secure messaging system and were supported with message templates and prewritten patient education handouts. Patient outcomes have been impacted and quality indicators for numerous chronic illness measures have been shown to correlate favorably with use of secure messaging."

Veterans Health Administration (VHA) - Initiated Care Coordination / Home Telehealth (CCHT) , a home care program designed to provide chronic care management for patients with diabetes, CHF, depression and other chronic conditions common to older veterans. Care coordinators, formal patient assessments,

selection of patient-appropriate technologies, as well as training for patients and caregivers were all planned prior to rollout. "Care-coordinators are able to use objective data transmitted by biometric monitors, complemented by messaging devices, which could identify knowledge deficits and negative health-related behaviors to determine if other interventions might be required." Provider concerns about how to manage large amounts of patient-generated data were addressed by assigning care coordinators (nurses or social workers) to review monitored data. The results over 4 years were a 25% reduction in bed days of care, and a 19% reduction in hospital admissions—plus very high levels of patient satisfaction.

Vanderbilt University Medical Center (VUMC) – When VUMC launched their MyHealthAtVanderbilt (MHAV) project, the main challenges were to develop a set of policies and procedures related to authentication, privacy and security, and management of the provider workload. "There are two access levels in MHAV: to access secure messaging with an established provider, a patient may register by supplying name, date of birth and social security number, but to access EHR data, in-person authentication is required. In response to concerns about patients viewing EHR data beyond their full comprehension, laboratory data were segmented into three categories."

- Vital signs data and was viewable without restrictions
- A category imposing a 7-day hold so providers could assist patients with data interpretation.
- A final category never viewable by patients. Included HIV test results and similarly sensitive data.

In order to manage the increased provider workload "to maximize the provider productivity, secure messages go to the provider's clinical group, and a nurse, administrative personnel or another member if the care team may respond to them. However, messages deemed clinically relevant…are forwarded to the patient's physician or another provider within a closed loop system." An audit of this system in 2006 determined that thousands of "clinically relevant" messages had remained unopened; therefore, additional mechanisms were put in place to ensure timely and certain response to all secure messages. Now, after 5 years of operation, approximately 26% of all VUMC patients are registered to use the patient portal capabilities—an enrollment rate above the national average.

Brigham and Women's Hospital developed the Patient Gateway to foster patient-provider communications and information sharing. "Patients who participated in the study were asked to use the eJournal to review clinical information and answer questions within specific modules (e.g., medications, allergies, health maintenance). To provide sufficient time for eJournal completion, patients were prompted 3 weeks prior to scheduled visits. In parallel, tools were developed to encourage providers to respond to eJournal submissions in advance of scheduled visits, and buttons were added to the EHR to support record updates consistent with patient's eJournal inputs…A majority of patients felt that the eJournal process had made them better prepared, and given the provider better information in advance of the visits. Providers in turn endorsed this system and assessed it to be time-neutral with no adverse impact on workflow."

The RTI White Paper provided 4 real world case studies of how Patient Generated Health Data is being applied. These four examples directly correlate with questions addressed in the NeHC Stakeholder Survey.

Kaiser Permanente & Veterans Health Administration

- 90.3% of stakeholders said that in terms of patient engagement with Health IT it's Important or Very Important that the Patient/caregiver engages with provider through electronic means (telemedicine).

Vanderbilt

- 42.7% of stakeholders identified enforcing privacy and security protocols as a key challenge with integrating electronic patient-generated health data.

Bringham and Women's (reinforces the healthdesign program when compared to the survey)

- 59.6% of respondents to the stakeholder survey currently deliver, or are planning to deliver in the next year, information electronically to patients.

The stakeholders were asked to what extent are the following types of electronic patient-generated data important in your organizations efforts to improve care. The responses indicating Important and Very Important are:

- 47.3% - Online journal for nutrition
- 39.3% - Online journal for mood
- 44.2% - Online journal for fitness

The White Paper identifies Technical, Operational, Legal and other issues facing the key players in using PGHD.

Technical Issues

- "What technical standards for interoperability are relevant or necessary to promote flow of PGHD?
  - Standard Data Definitions
    - RXNorm – medication terminology
    - LOINC – Laboratory terminology
  - Communication Protocols
  - Data Analystics
  - Other…
- "What new or existing authentication methods are needed to promote flow of PGHD? (Applies to both sender and receiver authentication)"
- "What common data set or minimum data set for PGHD is needed?"
- "How should HER architectures be modified to support the use of PGHD?"

Operational Issues

- What is the impact of PGHD on the healthcare provider's workflow?
- How does the volume of PGHD impact the workflow?
- With the increase of volume how does the staff deal with the burden of time to review all the PGHD?
- "Providers will likely need to understand their patient populations, and to target communications accordingly to where a greater need-and potentially greater impact-for receiving and reviewing PGHD are likely.
- What factors need to be addressed when promoting PGHD?
  - Financial Incentives

    - Costs
    - Education
    - Training
    - Level of Patient Engagement
    - Level of Provider Engagement
    - Level or Institutional Engagement
    - Technologies
- "Systems, devices, and tools for capturing PGHD are designed simply and do they offer ease of use for the patient and their designee?
- "Who would support the patient who is having difficulty with capturing and sharing PGHD, especially remotely?"

Legal Issues – Liability & Risk

- "Providers wanted to know when they were responsible for reviewing PGHD and in what time frame."
- "Providers wanted their patients to have clear and reasonable expectations about when PGHD would be reviewed and what kinds of data the provider was interested in receiving and reviewing."
- What is the risk/liability when there is a breakdown in the communication of PGHD?
- Who has Data Ownership? And how is the data used and under what circumstances?

"Other Issues

- Health Literacy (if low, is a big barrier)
- Time (if lacking, is a big barriers for providers and patients)
- Human or machine processing power (to make sense of large amounts of data, or data that are not obvious)
- Knowledge (to know what PGHD can be collected and what's worth collecting)
- Communication (to clearly understand what information is sought, by whom, so patients can be responsive and so providers can be supportive and directive, if needed)"

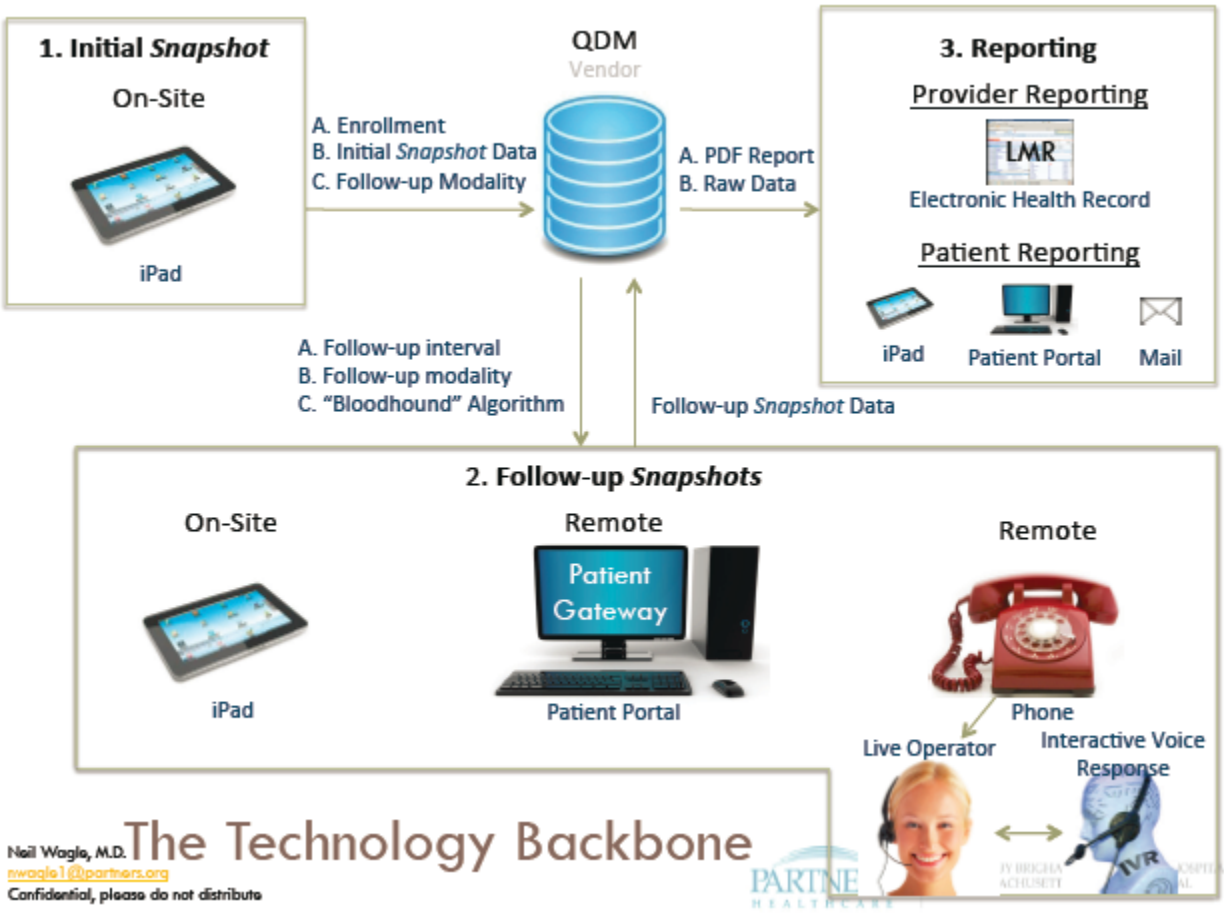
Partners Healthcare: Patient Reported Outcomes, Use Cases. February 2013

http://www.nationalehealth.org/ckfinder/userfiles/files/Partners%20Case%20Study%281%29.pdf
The goals of the Patient Reported Outcomes (PRO) Use Cases are

- "To orient care toward outcomes that matter to patients, creating a health system that learns
- To use PRO to improve the care of individual patients through better monitoring and improved responsiveness
- To use population-level data to set patient expectations and improve joint medical decision-making.
- To use aggregate data as the basis for internal comparative effectiveness research
- To publically report outcome measures in order to demonstrate quality and value"

Partners Healthcare asked patients to answer a survey provided to them on a tablet device during office visits and from home. These questions helped doctors understand the patient's condition and how treatment plans affected their daily living. The data was used for longitudinal research of how the patient was progressing with the treatment plan. The patient's preferences were taken into account of

how they would like to be contacted in the future, either by the phone or by the internet. If the internet option is chosen than the patient will receive the questionnaire vie email which can be completed online. If the phone was chosen then the patient will be called using an automated answering service (telehealth).



The patient would received feedback in the form of a snapshot that would provide a health scores, time trends/interval, and decision aids that can educate the patient on their health. The PRO had a separate tab in the patients EMR where providers could easily access the data, in the form of a flowsheet for example.

PRO improve patient care for an individual patient by

- "Systematically asking the right questions
- Putting the answers in the hands of the individual best suited to respond to them
- Monitoring a patient whether they present to care or not"

Patient Engagement at Geisinger

http://www.nationalehealth.org/ckfinder/userfiles/files/Patient%20Engagement%20At%20Geisinger%20Case%20Study.pdf

Geisinger pilot was with 42 clinic sites in 31 rural Pennsylvania counties. The goals of the study were to

- "Assess responses to the need for patient engagement in efforts to improve data quality in EHR's, identifying any shortcomings in current practices, and recommend responsive action.
- Illustrate current approaches to patient input, comparing approaches in health care to other fields
- Pilot test a patient feedback process"

Provide outpatients the ability to request updates to their record online (e.g., offer corrections, additions, or updates to the record) for medications through VDT using structured forms. The patient portal survey support allergies, immunization and demographic data elements. Other promising areas for patient sourced data are smoking status, advance directives, and family health history. Examples of EHR corrections are requesting an old medication to be removed from the active medication list, addition of a new over-the-counter medication, correction of birth date, and addition of family history of a chronic condition. Corrections are submitted online to clinicians.

The inclusion criteria for the pilot were patients with at least one chronic condition (e.g. asthma, COPD, etc…) and the patient has logged on to the MyGeisinger portal. Patients with upcoming appointments were invited to complete a medication feedback form prior to their office visit.

The workflow for the pilot was

- "Patients receive online form pre-populated with their EHR medication list
- Patients complete the form online and submit to Geisinger
- Pharmacists receive and process patient feedback
- Pharmacists update EHR
- Pharmacists notify physicians if shared decision making is needed

The results were positive. Patients are eager to provide feedback. "On average patient requested at least 2 changes per submitted form…a subsample analysis of 116 patients 56% of cases pharmacists accepted patient proposed changes."

NoMoreClipboards Case Study: An HIE-Populated Personal Health Record for Cardiac Revascularization Patients

http://www.nationalehealth.org/ckfinder/userfiles/files/NoMoreClipboards%20Case%20Study_An%20HIE-populated%20personal%20health%20record%20for%20cardiac%20revascularization%20patients.pdf
Patient population for this case study was two hundred patients from Parkview Physicians Cardiology Group (PPCG) who have recently undergone cardiac revascularization (coronary artery bypass graft and/or stent insertion). PPCG is a 24 physician cardiology practice, 3 primary offices and a dozen clinics; conduct 30,000 office visits and consultations as well as 40,000 hospital visits and consultations each year. When patients agreed to participate in the study, in person consent was obtained, the practice conducted baseline lab testing.

- Weight
- Blood pressure
- Lipid and HbA1c

- Online Survey (repeated at 6 months and 12 months)
- Daily Health diary in PHR, patients can self-enter and transmit their blood pressure, heart rate, blood glucose, height, weight and BMI to the practice.
- Daily reminders to complete and submit their diary information.

Personnel from Parkview Research Center (PRC) helped patients set up a NoMoreClipboards PHR account and provided training on use of the PHR, and PRC personnel helped patients complete the survey during the initial visit. In person consent was obtained. Submission of diary information and all messages are transmitted securely through the Med-Web HIE. A consumer in an HIE sponsored PHR or portal will be able to

- Preregister
- Request an appointment
- Request med refill

Patients have reviewed the clinical data imported into their PHR and have identified errors. As patients have access and visibility to their data, they are notifying the practice to correct data in the EHR. Patients provided with an ePHR had improved understanding of their conditions and adopted health behaviors. Patients who participated in electronic exchange and use these tools are more engaged, more likely to adhere to prescribed therapies and treatment plans, and more likely to enjoy improved outcomes and quality of life.

NoMoreClipboards Case Study: Identification, Authentication and Matching to Support Consumer Access to HIE Data

http://www.nationalehealth.org/ckfinder/userfiles/files/NoMoreClipboards%20Case%20Study_Identification%2C%20authentication%20and%20matching%20to%20support%20consumer%20access%20to%20HIE%20data.pdf

When a patient signs up for a PHR via the community portal, he or she will initiate the connection to the HealthBridge HIE in person at a participating covered entity associated with Margaret Mary Community Hospital (MMCH). Demographic elements are securely transmitted to HealthBridge using an HL7 PDQ message, and a PIX/PDQ manager looks for a match in the HIE's master patient index. The identification and authentication process will start with a check of the patient's government issued ID

- First name
- Last Name
- DOB
- Gender
- Last four digits of Soc #

Lab results are subject to a 72 hour embargo period, giving healthcare providers' time to review the results prior to patient access. In addition, certain lab results such as those associated with STD testing are excluded. Providing the data to patients has given us an opportunity to educate those patients.

Sujansky & Associates LLC: A Standards-Based Model for the Sharing of Patient-Generated Health Information with Electronic Health Records

http://www.nationalehealth.org/ckfinder/userfiles/files/Standard%20Model%20For%20Collecting%20And%20Reporting%20PGHI_Sujansky.pdf

This paper offers a "standards-based model to communicate data from patients' personal health devices to providers' EHRs in a manner that is feasible for both patients and provider. The model addresses what we believe are important requirements for the practical exchange of such data. The technical elements of the model are based on the features of personal health devices, health data repositories, and interoperability standards that already exist."

Sujansky proposes that "Patient-generated health information (PGHI) may comprise clinical parameters already familiar to medical providers (such as blood-glucose measurements or pain-scale observations), as well as "Observations of Daily Living " (ODLs) that are defined by patients and do not necessarily map directly to biomedical models of disease and illness (such as mood and sleep pattern). The model defined here applies to the sharing of both types of PGHI, to the extent that the patient-generated information can be references and represented in a standardized way. PGHI that is less well-defined and standardized may also be valued to patients and their providers, but it may not be amenable to sharing with EHRs as structured data."

6 technical and logistical requirements

- "Patients must be able to trust that their personally generated data will be shared only with their authorized providers
- A minimum of effort and complexity must be required for patients to collect data of interest to their providers, such as logs of blood glucose measurements, weight, and blood pressure.
- Providers must be able to control the flow of PGHI into their EHRs, because they may not wish to be medically and medico-legally responsible for monitoring patient-generated data that are automatically and continuously submitted to their EHRs.
- Providers must be able to distinguish patient-generated data imported into their EHRs from clinician-generated data, because providers may not trust the validity or accuracy of all data generated by patients.
- There must exist technical standards for uniformly representing patient-generated data in a manner that allows data generated by any home medical device of personal health application to be consumed by any provider EHR.
- There must exist technical standards for securely transmitting patient-generated data from any home medical device or personal health application to any provider EHR.

Below is a high level overview of the model proposed by Sujansky. "This model focuses on the communication of data from home medical devices to providers EHRs, either as raw data point or graphically summarized trends."

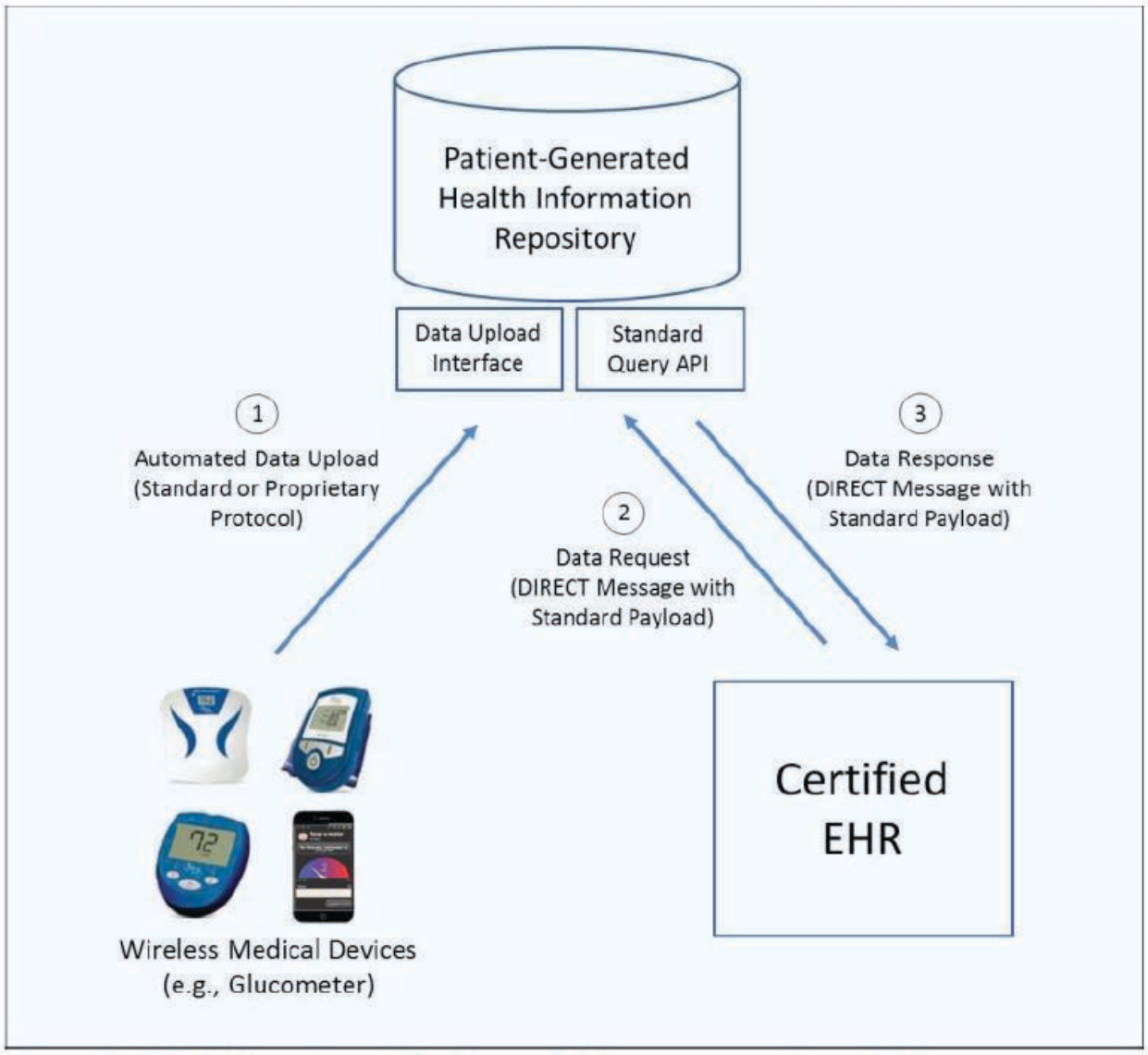


Figure 1. High-level architecture of the proposed model

Technical and workflow process:

- "Wireless devices that a patient uses at home automatically upload biometric measurements to the patient's record in a secure repository of PGHI.
- Via EHR, a clinician requests medical data for a specific patient by sending a DIRECT message to the DIRECT address of that patient's record in the PGHI repository.
- The standard query API sends a DIRECT message containing the requested data in a standard format (as a file attachment) to the requesting clinician's DIRECT address. The clinician or the clinician's EHR receives the DIRECT message, opens and interprets the attached file; stores and processes the data in the file, and displays the resulting information."

Challenges that this model address

- "Use of a trusted 3rd –party data repository that confers data ownership to the patient can enable patients to explicitly control who accesses their patient-generated data, while facilitating such access (when authorized) to clinicians practicing at various organizations and using various EHRs.

- The use of wireless home medical devices and other convenient data-collection tools can obviate the need for patients to manually record data, increasing the convenience to them of collecting these data in a consistent and reliable way.
- Patient-generated data will be explicitly requested by clinical to inform their care of the patients at the time the data are most useful, addressing clinicians' reservations about monitoring an automated and continuous feed of such data into their EHRs.
- The data-representation standards for retrieving patient-generated data from data repositories can include explicit denotations of the provenance of the data, addressing clinicians' need to evaluate the context and validity of medical information that may become part of the patient's official medical record.
- The use of DIRECT messaging as a secure transport protocol can increase adoption of the proposed model among commercial EHRs because support for DIRECT messaging will be a requirement for Stage-2 EHR certification by the fall of 2014.
- The use of existing industry standards for collecting medical-device data and for communicating such data to EHRs can leverage past standards work that is familiar to vendors of medical devices, data repositories, and EHRs, thereby accelerating widespread adoption of these standards to make the sharing of patient-generated data a practical reality."

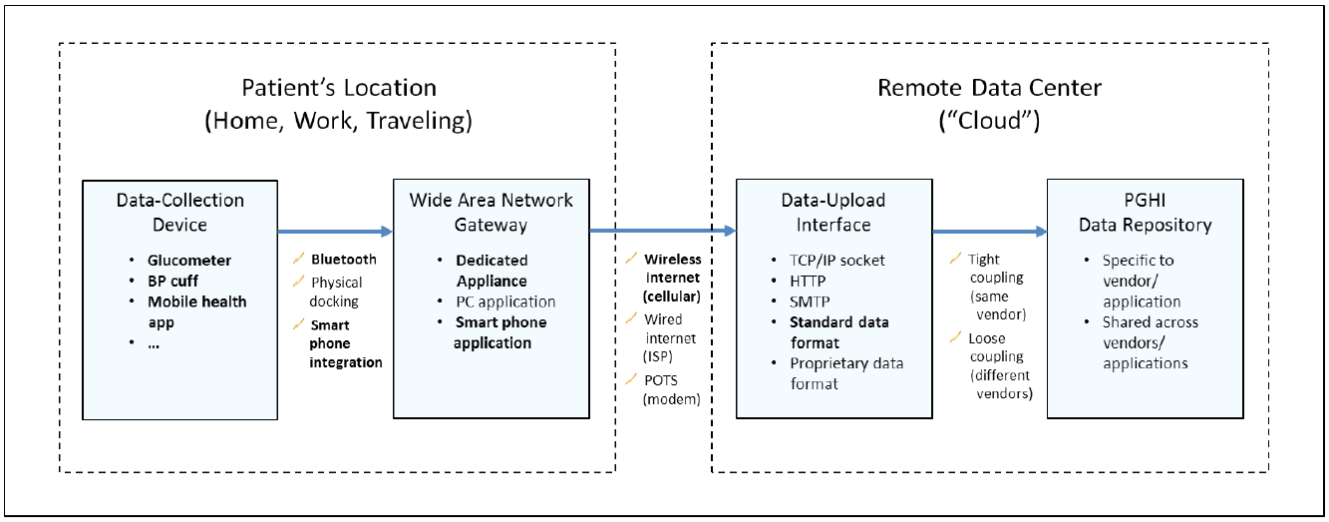


Figure 2. Components for the collection and storage of PGHI, including their various features and methods for transferring data among them.

"The DIRECT Project is an initiative sponsored by Office of the National Coordinator for Health Information Technology (ONC) to develop a set of interoperability standards and policies for the electronic exchange of patient health information."

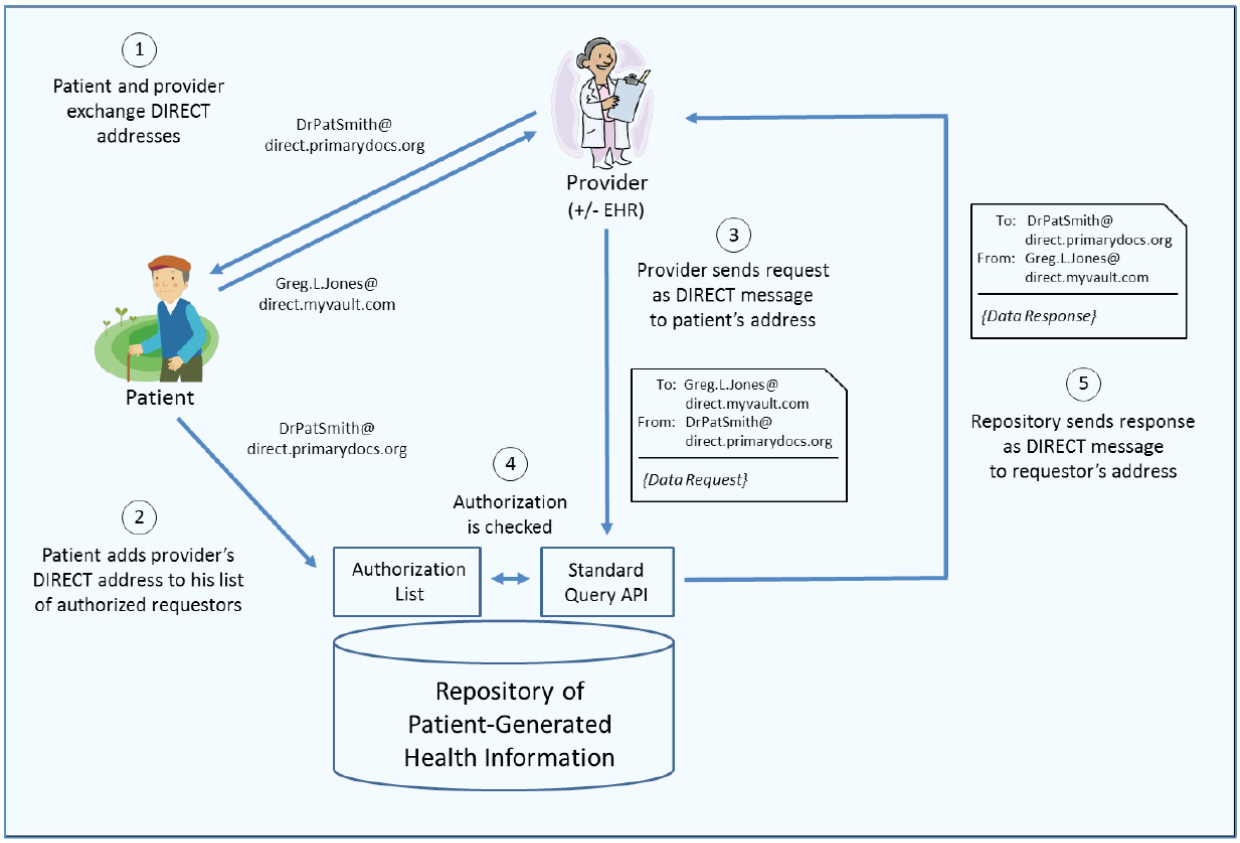


Figure 3. The use of DIRECT messaging to enable secure exchange of patient data between providers and patients' PGHI repositories.

Sujansky notes the following aspects of this model:

- "The patient's and provider's identities are fully characterized by their DIRECT address. No patient-matching logic or provider-identity verification is required on the part of the PGHI repository.
- The patient controls who may access his PGHI record by specifying the DIRECT address of authorized requestors.
- PGHI repositories accept requests from and send patient data to only those DIRECT addresses that have been authorized by the patient.
- Providers can access the PGHI from any repository that supports the standard query API, provided that their patient has authorized hem to access to his record in that repository.

Sujansky pointed out that "the standard model proposed here constitutes a "straw man" intended to foster thought, discussions and refinement through pilot implementations and improvements. Although the model is based on existing technologies and standards, the specific combination proposed here has not yet been used (to our knowledge) in a production setting to request and retrieve PGHI for providers and EHRs. "

Patient Generated Health Data (PGHD) Project
Questions for PGHD Case Study Examples
March 11, 2013

Questions for PGHD Case Study Examples

Goals:

1. Our goal is to identify a range of PGHD examples, especially *important* ones (i.e. by important, we mean: frequently occurring; or high value data for clinicians; high value to the patient; safety-related; high value to administrators or researchers; and many others…)
2. With a range of examples in mind, our goal is to identify the *processes that are served* (e.g. pt-dr communicating; documenting; decision-making; care planning; trouble-shooting a challenge or problem; improving patient performance; improving provider performance; and many others…)
3. With a range of examples in mind, our goal is to identify and understand *workflow factors and challenges* (i.e. known or anticipated issues that are important to address – for *patient workflow* and for *provider workflow*)
4. With real-world case study examples in mind, our goal is to identify positive learning (what worked) and negative learning (things to avoid)
5. With real-world case study examples in mind, our goal is to imagine… Should this be a routine practice, everywhere? If so, what would have to change for this to spread like wildfire?

To Reach These Goals:

1. Let's look at examples in detail, asking questions from multiple perspectives. The questions below are from the patient perspective, and the provider (and provider organization) perspective.
    a. What other perspectives are important? Clinical research? Health Information Management? C-Suite? IT? Post-marketing surveillance? Others?

Patient perspective:

- How will I be recruited, informed, and supported to contribute data? How do I initiate?
    - What expectations do I have about my role and my provider's use of my data?
- Do I have input into what data is collected?
- How/where am I expected to collect the data?
- At what point do I submit data (e.g. pre- or post-contact; periodically between contacts)
- What tools/functionality do I need to be able to submit the data
    - Who decides the form, amount, and content of the data (e.g. structured or unstructured; character limits; validation against a choice-list; etc.)
    - Who provides the tools I need? How do I get them?
- How do I receive feedback afterwards (e.g. is data discussed at next contact)?

Provider's perspective

- What data is accepted from patients, for what purpose?
    - What data do I request, and what data do I accept (or encourage) even if not requested?
    - When do I routinely request data - - from certain patients? For certain conditions or situations?
- Do I encourage patients to access and correct the record?
    - If so, who (provider side) handles correction requests?
    - Should patients make corrections directly in the EHR – for provider review AFTER the update? Sometimes, Always, Never? Why or why not?
- Who receives/reviews the data? (A range of individuals? A single individual? How do we decide?)
- What examples of technology/functionality are required for providers to receive patient-generated information? (also, what is the range…. i.e. Secure Messaging vs. 3rd party applications vs. Provider-side apps, and other flavors, etc.)
- Which PGHD is incorporated into the record? Which is not? How do you decide?
- How does a provider incorporate PGHD in the record? What process is used to accomplish this? What filtering or translation, if any, takes place as information is incorporated?
- What standards are important, and… are standards always or sometimes important?
- What challenges have been encountered by providers in getting patients to record and submit data?
- What range of mechanisms can be used to make sure a patient is identified, authenticated, and authorized to send data? (How is this done currently, and how might it be done differently in the future?)
- How do you identify the specific source of the data (e.g. from a specific medical device; or a visit summary from Dr. Y; or log entries recorded by a caregiver)? When is "specific source" information critical, important, or completely optional?
- Is the data structured, unstructured, or some of both (describe)?
    - When is unstructured data acceptable? Superior? Rejected? When is structured data acceptable? Superior? Rejected?
    - How does handling of data vary, if unstructured vs. structured?
    - Do you provide tools to your patient in order for them to structure the data so it is easier to integrate?

- What is done with the data, by whom and when?

    - Does any data flow directly into the EHR without prior clinician review? Is later provider review a requirement - - always, sometimes, or never? Why or why not?

- How many different ways is the data stored? By whom? For what reasons is the data stored one way versus another?

- What privacy and security protocols are used?

- Do clinicians trust the accuracy of electronic PGHD any differently than other patient data? What factors strengthen trust in the data accuracy? Weaken it? How are concerns about accuracy addressed?
- What type of data from patients (outside clinical encounter or labs) would you be most reluctant to lose? Most excited to use?
- What are some of the challenges and how are they being addressed?
- What have been the clinician workflow implications?
- How do you address risk or liability issues?

Patient Generated Health Data (PGHD) Project
Categorization of Questions for PGHD Case Study Review
March 27, 2013

Data to be collected

Collection

- Workflow
- Technology

Reporting

- Synthesis/Display
- Incorporation into the EHR
- Use

Critical Results

- Alerting
- Liability

Data to be Collected

- Is the data structured, unstructured, or some of both (character limits, validation against a choice list, describe)?
    - When is unstructured data acceptable? Superior? Rejected? When is structured data acceptable? Superior? Rejected?
    - Is the structured data in a standardized form?
    - Who and How does handling of data vary, if unstructured vs. structured?
    - Are tools provided to the patient in order for them to structure the data so it is easier to integrate?

- What type of data from patients (outside clinical encounter or labs) would you be most reluctant to lose? Most excited to use?

Collection

- Workflow
    - How is the patient recruited? How are they educated on the process?
    - What data is requested/submitted?
        - Is there other data reported that was not requested?
    - What feedback is provided? Is feedback provided if the data is not recorded in the health record? If not recorded is there an explanation as to why? (Incorrect data collected? Submitted incorrectly? Should the data be resubmitted?)
    - When is the data requested to be submitted?
        - Is this based on a certain condition or situation? (pre or post contact; periodically between contacts?)

- Does the patient have input as to what kind of data is requested/submitted? (flu-shot at retail clinic, existence or absence of family caregiver, reminders on functional status – wheelchair, etc…)
- How is the data collected?
  - Is a tool provided to the patient and where do they get it?
  - What is the process if the patient is unable to submit data due to language barriers, access, technical issues, etc…?
  - Who provides technical assistance or support?
- How is the date incorporated into the medical record?
  - Is there a filtration or translation of the data as it is incorporated into the medical record?
- What range of Mechanisms are used to make sure the person(s) submitting the data are authenticated, verified, or identified as the appropriate person(s) to be submitting the data? How is it done currently and how might it be different in the future?
- How is the specific source of the data identified? (i.e. medical device, visit summary from Dr. Y, caregiver)
  - When is the specific source information considered critical, important, or completely optional?
- Does the patient have access to their medical records?
  - Can the patient make corrections to the medical record?
  - Who at the practice handles correction requests?
  - Can corrections be made directly in the medical record?
  - Does the provider review these updates? Sometimes, Always, Never? Why or why not?
- What are the Workflow implications on the clinic?
- When does the process become a standard of care within the practice?
- Is submitting data easy and time effective? (filling out a form online vs. printing off the form for manual completion and brining copy to office visit)
- Has it been explained the value to the patients health and healthcare of contributing data?
  - How does this data enhance quality of life or help with a specific health condition?
  - How does the data help providers and their subsequent treatment recommendations?
- What are the propriety standards on the data?

- <u>Technology</u>
  - What examples of technology/functionality are required for providers and patients to exchange patient-generated information? (What is the range…. i.e. Secure Messaging vs. 3rd party applications vs. Provider-side apps, and other flavors, etc.)
  - What standards are important, and…are standards always or sometimes important?

- What challenges have been encountered by providers in getting patients to record and submit data? And what challenges have occurred with patients submitting the data?

Reporting

- Synthesis/Display
  - How many different ways is the data stored? By whom? For what reasons is the data stored one way versus another?
  - Is the information synthesized into a report or is all the raw data reported (or both)?
- Incorporation into the EHR
  - Did your EHR system easily accept my PGHD? What modifications needed to be made?
  - Which PGHD is incorporated into the record? Which is not? How do you decide?
  - Does any data flow directly into the EHR without prior clinician review? Is later provider review a requirement - - always, sometimes, or never? Why or why not?
  - What privacy and security protocols are used?
- Use
  - Who receives/reviews the data? (A range of individuals? A single individual? How is that decided?)
  - What is done with the data, by whom and when?
  - Do clinicians trust the accuracy of electronic PGHD any differently than other data submitted?
    - What factors strengthen trust in the data accuracy? Weaken it?
    - How are concerns about accuracy addressed?
  - Has the use of this data resulted in better patient care, lower costs, or learning (about how best to provide better care)?

Critical Results

- Alerting
  - Who gets alerted to abnormal values? How?
- Liability
  - How do you address risk or liability issues?

Questions (very general):

- What are some of the challenges and how are they being addressed?

Patient Generated Health Data (PGHD) Project
Taxonomy of PGHD
March 27, 2013

Purpose

As we examine examples of patient-generated health data, it is helpful to have a common language to describe characteristics of the examples. A taxonomy might provide that common language. In addition the people, processes, and technologies necessary for each PGHD initiative vary depending on its categorization along predictable axes. Understanding this can help organizations better prepare. So this taxonomy exercise fulfills several purposes:

1. Provide common language to discuss, compare, and contrast PGHD examples.
2. Permit categorization of planned PGHD implementations to help organizations prepare people, processes, and technology in their institution.

Caveat

Any categorization will be a work in progress, as new technologies arise and we learn more about PGHD. Our goal should be to create a framework that suffices for categorizing PGHD projects now and in the foreseeable future.

Process

We will use a "top-down" and "bottom-up" approach. We will rely on expert experience and opinion to create a draft taxonomy, and then we will analyze PGHD case studies to attempt to categorize them according to this framework. We will then revise the draft taxonomy as needed.

The Model

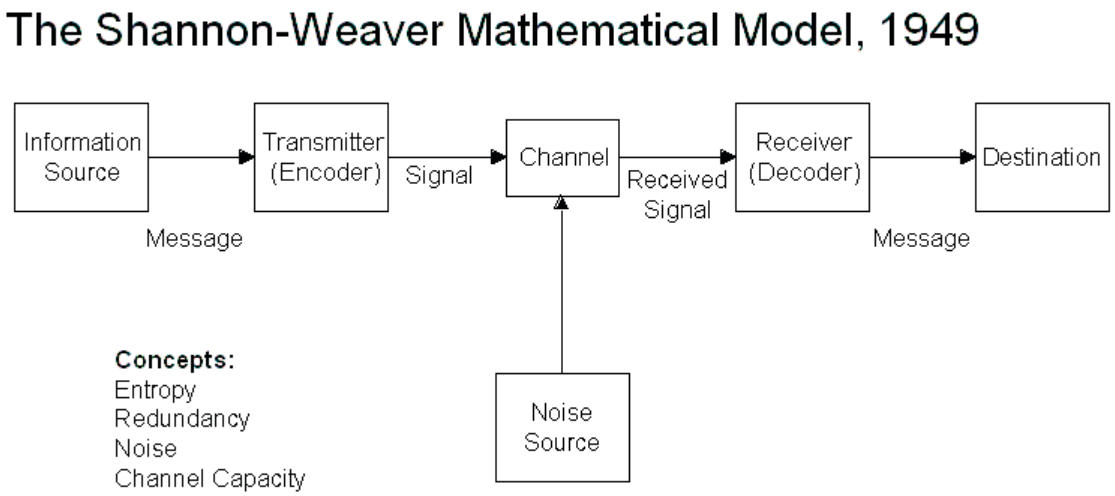


Figure 1: Shannon-Weaver Communication Model, Bell Labs, 1949 (from http://www.shkaminski.com/Classes/Handouts/Communication%20Models.htm)

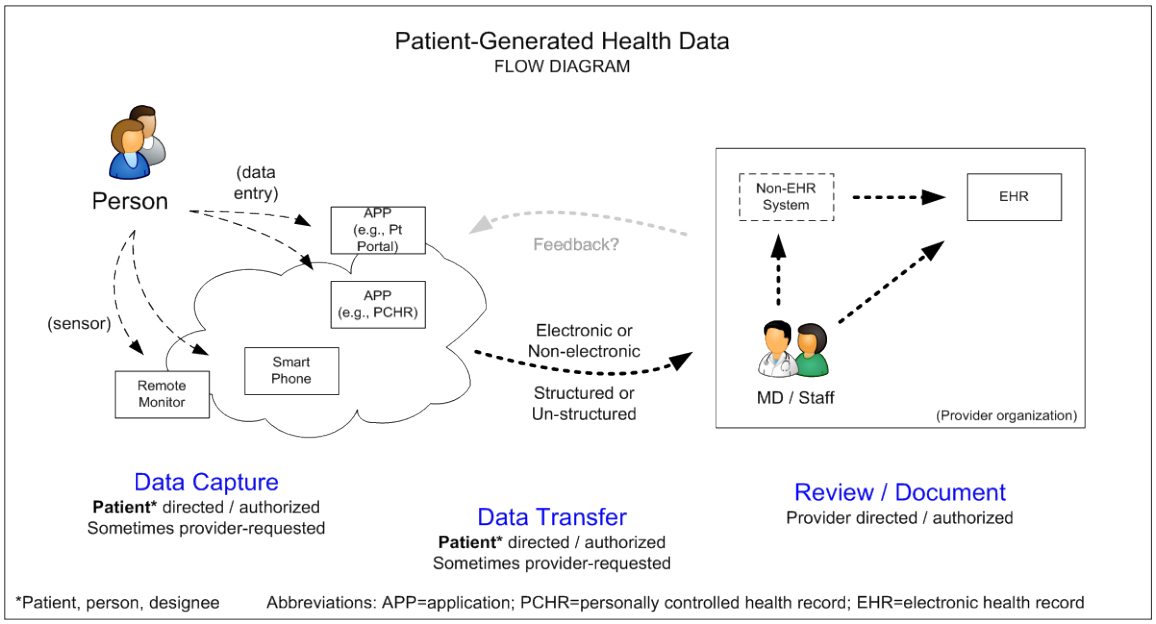


Figure 2: Patient-Generated Health Data Flow Diagram (from Patient-Generated Health Data White Paper, Shapiro et al., RTI International, 2012)

Taxonomy Types:
Technical Taxonomy

Patient role in Data Capture	Active	Passive		
Data Flow	Device-driven (push)	Patient initiated (push)	Provider initiated (pull)	Mixed
Request That Data Will Be Shared	Mutual	Clinician	Patient	Mixed
Synchrony	Asynchronous	Synchronous		
Data Type	Free Text	Structured Text (includes XML, CCDA, etc.)	Numerical	Other objects (image, audio, video, wave-forms, etc.)

Functional Taxonomy

I. "Static" Information
   a. Verification / Data Entry
      i. Demographic information
      ii. Insurance information
      iii. Medication Verification
      iv. Allergies
      v. Family History
      vi. Social History / Lifestyle Risk Factors (e.g. smoking)

II. Active Data
   a. Symptom / Functional Status Reporting
      i. Patient Reported Outcomes
         1. Risk assessments
         2. ADLs
         3. Functional Assessments
         4. Symptom scores

      ii. Adverse drug events
      iii. Adverse clinical events
      iv. Review of Systems
      v. Pictures/Videos

   b. Biometric Information
      i. Remote vital sign monitoring (e.g. blood pressure, weight)
      ii. Remote glucose or other lab monitoring
      iii. Graphical information (e.d. telemetry)
      iv. Nutrition or Physical Fitness monitoring

   c. Journaling

III. Proactive Data
    a. Care Planning
        i. Goal setting
        ii. Preferences
        iii. Values
        iv. Advanced Directives

IV. Retrospective Data
    a. Patient Experience of Care
        i. Satisfaction

Patient Generated Health Data (PGHD) Project
Use Case Examples
September 13, 2013

Submitted by Holly Miller (9/13)
Scenario: Patient updates health maintenance information

Key considerations	Response
Scenario (patient directed exchange)	Patient updates health maintenance information PCP has requested patient have some dx specific tests and studies and some age/gender based health maintenance studies Patient has these done at outside facilities and informs PCP that the tests studies have been completed and includes the results
What information is the patient capturing, and delivering to the provider's organization?	Dates and times of the studies and visits to specialists as well as the consequent reports and results (e.g. ophthalmology and report), X-ray (e.g. mammogram); lab (e.g. HgbA1C, or lipid panel); procedure report (e.g. colonoscopy), etc., etc.
How is the information being delivered by the patient or caregiver?	Potentially the patient has received all of their information to their portal and is now forwarding the information to the PCP
How is the information received in the practice?	Via "Direct" or some other technology from the patient portal into the PCP's EHR; wherever possible the PCPs EHR is able to store the received data as discrete data once reviewed by the PCP. Health maintenance or disease management "schedule for the patient is updated with the new information.
Who receives the information at the practice?	EHR To be reviewed by the PCP
How is the information reviewed by the practice and by whom?	As above
Who responds to the patient or caregiver, and how?	PCP or delegate
How and under what circumstances is the information being recorded?	Explained above
What is the outcome/value of the process?	Consumer convenience, faster service information available to those who need it ; avoid duplicate testing, etc.
What policies should be in place to support these activities?	Practice policies and agreements regarding workflow and expectations
What value is illustrated in this Use Case? Costs (to whom)? Benefits?	Care quality and efficiency

Submitted by Virinder Batra (9/13)
Scenario: Blue Button Correction

Key considerations	Response
Scenario: Blue Button Correct	As part of View Down Load Transmit in MU2, the Patient now can see his/her Summary record in a CCD. If there is any discrepancy in the record, the patient should be able to flag an error in any of the data elements; Request the value of the data element to be changed to the new value supplied. These data elements could be any element in the list i.e. Demographics, Medications, Procedures, Allergies etc. A common process could be labeled as 'Blue Button Correct'
What information is the patient capturing, and delivering to the provider's organization?	Changes to the elements in the CCD delivered to the patient by the provider
How is the information being delivered by the patient or caregiver?	As an CDA document attached to a secure message sent by the patient to the provider
How is the information received in the practice?	As an CDA document attached to a secure message sent by the patient to the provider
Who receives the information at the practice?	The administrative staff at the providers office
How is the information reviewed by the practice and by whom?	The doctor at the practice reviews the changes and approves the corrections to be made in the EMR record. Possibly EMR's will develop reconciliation functions which will show the current and the proposed changes in one screen to make it easier for the physician to 'accept and approve' multiple changes in one session.
Who responds to the patient or caregiver, and how?	When the changes are accepted, automatic notifications are sent to the patient that changes have been accepted. If a change is denied then a reason is specified
How and under what circumstances is the information being recorded?	After it is approved by the physician
What is the outcome/value of the process?	The quality of the EMR record for a patient is improved, and there is a feedback loop to identify errors. The patient helps in 'verifying' his record
What policies should be in place to support these activities?	Policies to accept changes into EMR Definition of the number of days within which request for change should be responded to
What value is illustrated in this Use Case? Costs (to whom)? Benefits?	More accurate record for Patient Patient helps in keeping his record accurate

Scenario: Pre-visit Data Collection

Key considerations	Response
Scenario	Pre-Visit Data Collection Scenario
What information is the patient capturing, and delivering to the provider's organization?	Family History, Social History, Demographics, Medications , Problems, and other data only the patient knows
How is the information being delivered by the patient or caregiver?	Form Based System provided by the Patient Portal system. Data collection request is initiated by the provider, in preparation for a future appointment
How is the information received in the practice?	Transformed to a C-CDA document and sent to the provider by the patient through a patient portal
Who receives the information at the practice?	The administrative staff at the providers office
How is the information reviewed by the practice and by whom?	Information reviewed by the administrative staff, and attached to the EMR record of the patient
Who responds to the patient or caregiver, and how?	Admin staff/Provider respond if there is any questions on the information
How and under what circumstances is the information being recorded?	The EMR system allows for merging the Patient Supplied data to the EMR record, keeping the provenance of the data intact
What is the outcome/value of the process?	Reduced time for 'processing' a patient at the providers' office.
What policies should be in place to support these activities?	Polices to make sure that the patient supplied data is included in the patient record, before the appointment and the doctor has access to the data at the time of the encounter with the patient
What value is illustrated in this Use Case? Costs (to whom)? Benefits?	Value to patient: Patient can enter all the data at his/her convenience Value to Provider: Saves the time for the doctor to collect the information

Submitted by Frank Fortner (9/12)
Scenario: Demographic update to the EMR

Key considerations	Response
Scenario	Demographic Update to the EMR
What information is the patient capturing, and delivering to the provider's organization?	Change in address, name, phone number, insurance, etc.
How is the information being delivered by the patient or caregiver?	Secure email or submitted through a form in a patient portal, possibly including an uploaded image of the new insurance card
How is the information received in the practice?	Secure messaging
Who receives the information at the practice?	Office staff
How is the information reviewed by the practice and by whom?	Office staff verifies insurance
Who responds to the patient or caregiver, and how?	Office staff
How and under what circumstances is the information being recorded?	Office staff updates EHR
What is the outcome/value of the process?	Increased efficiency; time savings; easier to stay connected with the patient
What policies should be in place to support these activities?	
What value is illustrated in this Use Case? Costs (to whom)? Benefits?	The benefit is having an accurate way to contact the patient and/or coordinate insurance payments, saving time when the patient presents to the office.

Scenario: Update Patient Symptoms

Key considerations	Response
Scenario	Update Patient Symptoms
What information is the patient capturing, and delivering to the provider's organization?	Change in symptoms or a NEW symptom, possibly related to an ongoing episode of care. E.g. the patient is now experiencing shortness of breath or palpitations.
How is the information being delivered by the patient or caregiver?	Secure email or submitted through a form in a patient portal.
How is the information received in the practice?	Secure messaging or a direct link to the data in the portal provided appropriate access has been granted
Who receives the information at the practice?	Office staff or PCP.
How is the information reviewed by the practice and by whom?	PCP
Who responds to the patient or caregiver, and how?	Response may / may not be necessary. In some cases, the new information may shed light on a "mystery diagnosis" and PCP may ask staff to coordinate an appointment.

Key considerations	Response
How and under what circumstances is the information being recorded?	Office EHR is updated if deemed necessary.
What is the outcome/value of the process?	More accurate picture of patient's condition
What policies should be in place to support these activities?	
What value is illustrated in this Use Case? Costs (to whom)? Benefits?	The benefit is having accurate health information so physicians can better diagnose and treat patients.

Scenario: Update Medications Currently being taken

Key considerations	Response
Scenario	Update Medications Currently Being Taken
What information is the patient capturing, and delivering to the provider's organization?	Patient documents changes in which medications are currently being taken vs. what they have been prescribed
How is the information being delivered by the patient or caregiver?	Submitted through a form in a patient portal and stored in a clinical data repository
How is the information received in the practice?	Secure email notifying PCP of a change in medication status … OR simply stored a database which can be accessed perhaps at a hospital ED
Who receives the information at the practice?	Office staff or PCP or electronic interface to office EHR
How is the information reviewed by the practice and by whom?	PCP or nurse practitioner
Who responds to the patient or caregiver, and how?	Response may / may not be necessary. In some cases, the new information may prompt a call to discuss, for example, the patient's decision to discontinue a med.
How and under what circumstances is the information being recorded?	Office EHR is updated if deemed necessary.
What is the outcome/value of the process?	Accurate medication administration information from the best source of truth – the patient.
What policies should be in place to support these activities?	
What value is illustrated in this Use Case? Costs (to whom)? Benefits?	The benefit is knowing (out of all meds prescribed) which ones a patient is currently taking. For example, in an emergency setting of care where the patient may not be coherent, this data could still be accessed from the chart. In an inpatient setting, this information could be used for medication reconciliation.

Submitted by James Walker (9/9)
One thought regarding device agnosis and “have-not-centered care”:

35% of Americans have a dumb phone.

Until smart phones get cheaper or we arrange for have-nots to be less disadvantaged, let’s design systems that incorporate dumb phones.

Submitted by Susan Woods (9/9)

Data Types
Possibilities are extensive. To be helpful for a use case discussion, my view of high-value types are highlighted:

a. Personal profile information
b. Administrative information
c. Preferences & Permissions
d. Medical history input
    a. Pre-visit agenda (unstructured or mixed text/structured to specific questions)
    b. Subjective part of note (!!)
e. Tracking data
    a. Biometric monitoring: blood pressure, sugar, weight (structured)
    b. Comments or patient-reported symptoms, side effects, information
f. Medication information
    a. prescribed or obtained elsewhere, OTC and herb/supplements
    b. Comments on current medication lists (taking, not taking, taking differently)
g. Surveys/structured input (specific issues or cohorts, e.g. mental health, cancer Rx, dialysis, etc.)
h. Patient experience
i. Shared care plan – read/write – review/modify/accept
j. End of Life care

Data Review
I like a **solicited** data concept. Given that we don’t have resources to review continuously streaming data.

However, like secure email (IMO, a great example of PGD!), patients need to be able to **PUSH** data.

Some general thoughts --

- Not all data needs to be reviewed and should be for the purposes of patients themselves (think: glucometers)

- Most data can be reviewed ‘just in time’, when needed
- Notifications of out-of-bound or concerning data (high/low BP, depression scores) must go to the PATIENT (go see your provider)
- Workflow issues and development efforts abound for
    - Health care team review of data
    - Integrating data into the EHR

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