1. **TITLE PAGE**

   a. **Title**: Improving Healthcare Quality with User-Centered Patient Portals

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2. STRUCTURED ABSTRACT

a. Purpose: To achieve patient-centered care, healthcare organizations must share medical data with patients. However, barriers to widespread diffusion and effective use of this information are limiting impact. The purpose of this award was to study ways to improve electronic patient portals.

b. Scope: This 4-stage project studied electronic patient portals, usage, and outcomes in chronic disease and primary care.

c. Methods: Qualitative methods were applied to understand patient information management needs. Several retrospective cohort studies were conducted using portal data. Human factors/human-computer interaction methods were used to improve portal usability. The PI also underwent training in human factors, quality measurement, use of electronic health record data for research purposes, and data analysis methods.

d. Results: More than 20 peer-reviewed papers on patient information management needs, adoption and impact of novel portal features, and human factors analysis and iterative development of patient portal functions. Leveraging the work of the current grant, the PI has obtained an R01 on consumer informatics, a foundation grant on the application of human factors to health information technology, and a competitive intramural grant on social determinants of health.

e. Key Words: electronic patient portals, consumer health information technology, health literacy, human factors, electronic health records

3. PURPOSE

The long-term goal of this research was to learn how to empower patients to assume a central role in the management of their health and health care through health information technology, specifically, electronic patient portals offered by healthcare organizations.

Specific Aim 1: To develop a patient information management needs framework for health activities. This hypothesis-generating study was intended to involve semistructured interviews with patients and providers focusing on management of chronic disease. The goal was to identify health-related tasks and health information management activities of primary concern to patients.

Specific Aim 2: To validate the patient information management needs framework. This aim was intended to assess several quantitative hypotheses about electronic patient portal use, focusing specifically on use of features from patient portals that met needs identified in the framework.

Specific Aim 3: To apply the patient information management needs framework to improve task-technology fit of consumer technologies. This aim was designed to involve cycles of user testing and technology modification designed to improve both usability and ability to meet patient information needs. The purpose was to improve the usability of the technology, a necessary precursor to impact.

Specific Aim 4: To evaluate the effect of use of consumer health IT on healthcare quality over time. NOTE: This specific aim was altered with AHRQ permission after grant award. Instead of evaluating use of the entire patient portal (an aim that had at that point already been accomplished by other investigators), the aim was altered to evaluate the use of a specific newly launched feature within the electronic patient portal, which was a function that allowed the upload of patient-generated health data.

Training aims: The overarching training and educational goal of this K01 award was to support the education the PI required to accomplish the stated research goals, and to position her to become an independent researcher in patient-centered health information technology at the intersection of informatics and health services research. The training aims involved formal academic coursework, intensive short courses, pragmatic training through mentorship, and grant writing.

4. SCOPE

Background: To achieve patient-centered care, patients need personalized, timely, and understandable medical information. Electronic patient portals have demonstrated efficacy for a number of targeted outcomes, but have not yet demonstrated broad effects on healthcare quality in practice. Models of technology impact suggest that this is because the technologies have not diffused broadly enough, and users are not using them optimally. Barriers to adoption and effective use include poor usability and portal designs that focus on facilitating organizational goals rather than patients' goals. We propose that consumer technologies will improve healthcare quality only after they are widely adopted and used, and that adoption will rise only when the technologies match both patient abilities and their needs.

Context: The HITEC Act of 2009 established the federal EHR incentive program (commonly called the "meaningful use program"), which offered financial incentives to healthcare providers and organizations for adopting and using electronic medical records. As part of this incentive program, healthcare organizations had to guarantee timely patient access to electronic medical data, and subsequently, adoption of electronic patient portals grew precipitously.

At the time this award was written, evidence of their impact on healthcare quality was slim. It appeared that electronic patient portal adoption rates were rising only slowly, with significant disparities meaning that traditionally disadvantaged patient groups were using them even less frequently. This suggested that from a population/public health perspective, impact would continue to be limited. On top of more commonly recognized barriers such as lack of Internet access and low health literacy, a contributing factor appeared to be poor designs that emphasized the underlying structure of the database or the needs of the healthcare organization rather than the priorities and needs of the patient users.

Settings: This series of studies was conducted in three healthcare organizations.

The *Weill Cornell Provider Organization* is a multispecialty ambulatory practice organization with about 800 faculty healthcare providers and more than 1 million ambulatory patient visits per year. The Weill Cornell Connect patient portal was launched in 2010 and started being promoted to all patients in 2011. The portal currently serves about 50,000 registered patients.

The *Institute for Family Health* (IFH) is a network of federally qualified health centers providing safety net primary care to a predominantly low-income population in New York City and in rural areas north of the city. IFH has a highly racially, ethnically, and socioeconomically diverse population, with nearly one quarter uninsured and another quarter covered by Medicaid. In 2011, IFH developed an innovative collaboration with the National Library of Medicine in order to provide patients with single-click access from highlighted medical terms appearing in the patient portal to the NLM's MEDLINEplus Connect patient education materials. During the time of this award, the IFH portal had approximately 20,000 registered patient users.

NewYork-Presbyterian Hospital, one of the nation's top-ranked hospital systems, serves as the teaching hospital for both the Weill Cornell Medical College and the Columbia University College of Physicians and Surgeons. The hospital system is an international referral center and also serves a diverse urban population locally. During the grant period, NewYork-Presbyterian offered an electronic patient portal called MyNYP, but support for this MyNYP product was transferred from Microsoft HealthVault to a proprietary electronic patient portal vendor. Due to historical reasons, NewYork-Presbyterian has different inpatient and outpatient health information technology systems, and MyNYP was connected to the inpatient system to give patients access to their inpatient data.

Participants:
Core studies
1. Study 1 was a qualitative interview study that included 22 ambulatory patients with multiple chronic conditions and 7 ambulatory providers recruited from ambulatory clinics at Weill Cornell and IFH. Inclusion criteria were that patients had to have multiple chronic conditions, and be able to communicate in English; they did not have to have experience using consumer health information technology. Included patients had an average of 3.5 chronic conditions and relationships with an average of 5 healthcare providers. (2 manuscripts[1,2] and 2 conference abstracts[3,4])
2. Study 2 was a retrospective cohort study assessing several hypotheses surrounding use of an electronic patient portal and features within it. The cohort was designed to include Institute for Family Health patients with electronic patient portal accounts who had or had not used various features of the portal. Total sample size was 129,738 patients, including 30,692 portal users. (2 manuscripts[5,6])

3. Study 3 was a human factors study including 23 adult patients recruited from NewYork-Presbyterian Hospital. For user testing, participants had to be 18 to 95 years of age, able to communicate in English, able to use a computer, and either have a chronic condition or the manager of care for a person with a chronic medical condition. (1 manuscript[7] and 1 poster[8])

4. Study 4 was a retrospective cohort study examining adoption, use, and outcomes associated with using a newly deployed portal feature that allows patients to upload patient-generated health data. Patients were included if they had uploaded at least 3 values over any 9-month period; healthcare providers were included if they had placed the order for the flowsheet that allowed these patients to upload their values to the electronic patient portal. The study included 16 healthcare providers in four departments, and 53 adult patients. Of the patients, 23 were pregnant women with a high-risk pregnancy, and 30 were nonpregnant adults with chronic diabetes. (1 manuscript[9])

Newly developed studies

In addition to the planned research studies, several novel studies were developed to extend planned projects or apply findings in additional consumer health informatics contexts.

5A. Developed in collaboration with the PI's graduate student and one of her K award mentors, this study applied qualitative methods similar to those in study 1 to identify the information needs of healthcare providers when reviewing patient-generated health data. This study involved interviews with 5 rheumatologists. (1 manuscript[10])

5B. An experimental study using methods similar to those in study 4 assessing the impact of human factors interventions on patient comprehension of medication instructions. This study, funded by a competitive intramural grant, included 951 respondents from an online panel, with a mean age of 36, and 38% had less than a 4-year college education. (1 manuscript[11])

5C. A user-centered iterative development study using methods similar to those of study 4 was developed in collaboration with Memorial Sloan-Kettering Cancer Center. This study included 13 cancer survivors ranging in age from 35 to 70, and 25 advisory board members that included 5 patient partners. (1 manuscript[12])

5D. As a Cornell faculty member, the PI has the ability to include questions to ongoing statewide and national surveys conducted by Cornell Survey Research Institute at no or low cost. She leveraged knowledge and skills gained from the current project to publish survey papers on adoption of electronic patient portals (1000 telephone respondents),[13] patient perceptions of electronic medical records (1000 telephone respondents),[14] and patient perceptions of mobile health (1000 respondents).[15]

5E. While examining patient use and perspectives on electronic patient portals, the PI discovered several anomalies in privacy policies during the adolescent years. In collaboration with a graduate student and collaborators at Georgia Tech, this led to a nationwide interview study (25 participating chief medical information officers and other medical center leadership),[16] a nationwide survey study (1000 telephone respondents),[17] and a key informant study.[18]

Incidence, Prevalence: Not applicable

5. Methods

Core studies

1. Semistructured interviews were conducted with patients and providers. Patients were eligible if they had multiple chronic conditions and were in regular care with one of two medical organizations in New York City; health care providers were eligible if they had experience caring for patients with multiple chronic conditions. as well as participation in a diabetes education group to triangulate emerging themes. Data were analyzed using grounded theory and thematic analysis. Recruitment and analysis took place iteratively until thematic saturation was reached.

2. In this retrospective cohort study, 3 years of patient data (including clinical data and patient portal usage data) were extracted from the electronic health record for analysis with multiple logistic regression.

3. The PI and two student evaluators applied heuristic usability evaluation and conducted 23 individual user testing sessions with patients with chronic disease or managing the care of family members with chronic disease. Evaluation and development/improvement were conducted iteratively. User testing and analysis of qualitative data were both conducted from the perspective of a task-technology fit framework, to assess the degree of fit between the portal and patient work.

4. This was a retrospective observational study of adult ambulatory patients who used the PGHD tool between 2012 and 2016. Patient data was extracted from an electronic health record, and descriptive analyses were conducted to compare data uploaders with a comparable group of patients with diabetes diagnoses and patient portal accounts seen by the same healthcare providers.

5A. A pilot analysis of smartphone mobility data was done with a single RA patient, followed by assessment of rheumatologists' needs for patient data through semi-structured interviews; and then by evaluation of the visual format of the RA data using scenario-based usability methods with the same rheumatologist participants.

5B. We selected examples of dosing instructions from after-visit summaries in a commercial electronic health record. A demographically diverse sample of parents and adult caregivers was recruited from an online panel to participate in an English language experiment, in which they received a comprehension questionnaire with either original after-visit summary instructions or instructions revised to comply with federal and other sources of plain-language guidance.

5C. We conducted user testing and rapid application development of a newly developed symptom reporting system that supports home-based recovery by inviting patients to self-report symptoms in the days after surgery and then receive an immediate feedback report giving context for their reported symptoms.

5D. Questions were these surveys are developed by the investigators and submitted to Cornell SRI for competitive peer-review. Selected questions undergo cognitive pilot testing and/or revised for to remove ambiguity. The random-digit-dial telephone surveys are conducted on a dual sampling frame of landline and cell phone numbers. When a line is answered, the invitation is issued to the person with the closest birthdate. The Empire State Poll samples within New York State, and sampling weights are applied to produce a weighted sample reflective of state demographics. The Cornell National Social Survey sample across the continental United States, using a simple random selection, with no survey weights. After descriptive analysis, logistic models were constructed by including factors statistically significant in bivariate analyses.

5E. Within a sampling framework that ensured diversity of geography and medical organization type, we used purposive and snowball sampling to identify key informants. Semi-structured interviews were conducted and analyzed with inductive thematic analysis, followed by a

member check. For the subsequent survey study, we used the Cornell National Social Survey (described above). We added questions about a) whether parents should be able to see their 16-year-old child's medical record, and b) whether teens would avoid discussing sensitive issues (sex, alcohol) with doctors if parents could see the record. Hypothesizing that highlighting the rationale for adolescent privacy would change opinions, we conducted an experiment by randomizing question order.

6. RESULTS

1. **Sick people do not always welcome access to their medical data**

- **You Get Reminded You're a Sick Person": Personal Data Tracking and Patients With Multiple Chronic Conditions Results:** Interviews were conducted with 22 patients and 7 health care providers. The patients had an average of 3.5 chronic conditions, including type 2 diabetes, heart disease, chronic pain, and depression, and had regular relationships with an average of 5 providers. Four major themes arose from the interviews: (1) tracking this data feels like work for many patients, (2) personal medical data for individuals with chronic conditions are not simply objective facts, but instead provoke strong positive and negative emotions, value judgments, and diverse interpretations, (3) patients track for different purposes, ranging from sense-making to self-management to reporting to the doctor, and (4) patients often notice that physicians trust technologically measured data such as lab reports over patients' self-tracked data. **Conclusions:** Developers of consumer health information technologies for data tracking (such as diet and exercise apps or blood glucose logs) often assume patients have unlimited enthusiasm for tracking their own health data via technology. However, our findings potentially explain relatively low adoption of consumer HIT, as they suggest that patients with multiple chronic illnesses consider it work to track their own data, that the data can be emotionally charged, and that they may perceive that providers do not welcome it. Similar themes have been found in some individual chronic diseases but appeared more complex because patients often encountered "illness work" connected to multiple diseases simultaneously and frequently faced additional challenges from aging or difficult comorbidities such as chronic pain, depression, and anxiety. We suggest that to make a public health impact, consumer HIT developers should engage creatively with these pragmatic and emotional issues to reach an audience that is broader than technologically sophisticated early adopters. Novel technologies are likely to be successful only if they clearly reduce patient inconvenience and burden, helping them to accomplish their "illness work" more efficiently and effectively.[2]
- **The Invisible Work of Personal Health Information Management Among People With Multiple Chronic Conditions: Qualitative Interview Study Among Patients and Providers Results:** Four major themes arose: (1) Responsibility for managing medical information: some patients perceived information management and sharing as the responsibility of health care providers; others—particularly those who had had bad experiences in the past—took primary responsibility for information sharing; (2) What information should be shared: although privacy concerns did influence some patients' perceptions of sharing of medical data, decisions about what to share were also heavily influenced by their understanding of health and disease and by the degree to which they understood the health care system; (3) Methods and tools varied: those patients who did take an active role in managing their records used a variety of electronic tools, paper tools, and memory; and (4) Information management as invisible work: managing transfers of medical information to solve problems was a tremendous amount of work that was

largely unrecognized by the medical establishment. **Conclusions:** We conclude that personal health information management should be recognized as an additional burden that MCC places upon patients. Effective structural solutions for information sharing, whether institutional ones such as care management or technological ones such as electronic health information exchange, are likely not only to improve the quality of information shared but reduce the burden on patients already weighed down by MCC.[1]

2. **Patient-friendly policies and affordances can improve access to medical records**

- **Expanding access to high-quality plain-language patient education information through context-specific hyperlinks.** A federally qualified health center (FQHC) sought to help patients interpret their records by embedding context-specific hyperlinks to plain-language patient education materials in its portal. We assessed the impact of this innovation through a 3-year retrospective cohort study. A total of 12,877 (10% of all patients) in this safety net population had used the MPC links. Black patients, Latino patients comfortable using English, and patients covered by Medicaid were more likely to use the informational hyperlinks than other patients. The positive association with black race and Latino ethnicity remained statistically significant in multivariable models that controlled for insurance type. We conclude that many of the sociodemographic factors associated with the digital divide do not present barriers to accessing context-specific patient education information once in the portal. In fact, this type of highly convenient plain-language patient education may provide particular value to patients in traditionally disadvantaged groups.[6]

- **Access policy and the digital divide in patient access to medical records. Results:** In 2011, members of socioeconomically disadvantaged groups were less likely to receive offers to use the portal and subsequently to use it. In 2014, black patients became just as likely as other racial groups to use the portal, but publicly insured and uninsured patients were still less likely to become users. Uptake of the mobile app was slow. Conclusions: Replacing an opt-in policy with a universal access policy was associated with a large reduction in socioeconomic disparities between those who did and did not access their medical records. However, a small digital divide remained evident in use of the technology, probably due to structural factors beyond the control of the healthcare system such as lack of computer access by less affluent patients.[5]

3. **Patient-friendliness can be additionally improved by considering patient work**

- **Applying a Task-Technology Fit Model to Adapt an Electronic Patient Portal for Patient Work.** Ability to complete health information management tasks, perceived usability, and positive comments from users improved over the course of the iterative development. However, patients still encountered significant difficulties accomplishing certain tasks such as setting up proxy accounts. The problems were most severe when patients did not start with a clear understanding of tasks that they could accomplish. In exploring the portal, novice users frequently described anecdotes from their own medical history or constructed fictional narratives about a hypothetical patient. We conclude that chronic illness imposes a significant workload on patients, and applying a task-technology framework for evaluation of a patient portal helped improve the portal's fit to patient needs. However, it also revealed that patients often lack a clear understanding of tasks that would help them accomplish personal health information management. Portal developers may need to educate patients about types of patient work involvingmedical centers, in a way that developers of clinical information systems

do not need to do. An approach to doing this might be to provide narratives about hypothetical patients.[7]

4. Despite the potential for PGHD to improve patient care, providers are slow to adopt it

- **Early adopters of patient-generated health data upload in an electronic patient portal** Over 4 years, 16 providers chose to use the new PGHD tool, and 53 adult patients used it to upload 3 or more blood glucose values within any 9-month period. Of these patients, 23 were pregnant women, and 30 were nonpregnant adults with diabetes. Uploaders had more encounters and portal logins than comparison patients but did not differ in socioeconomic status. Among the chronic disease patients, uploaders' mean hemoglobin A1c and body mass index (BMI) both dropped significantly in the months after upload. We conclude that the potential value of PGHD in healthcare, the rate of adoption of a tool allowing patients to upload PGHD to their provider's EHR has been slow. Among chronic disease patients, PGHD upload was associated with improvements in blood glucose control and BMI, but it is possible that the changes were due to increased motivation or intensive changes in medical management.[9]

5A. Less is more when it comes to PGHD from providers' perspective

- **Smartphone Data in Rheumatoid Arthritis – What Do Rheumatologists Want?** Reducing a large amount of patient data into a color-scale mobility index superimposed on a calendar was able to help rheumatologists make sense of passive mobility measures from the smartphone that the rheumatologists confirmed would be clinically relevant. This assessment of clinician data needs and preferences demonstrates the potential value of passively collected smartphone data to resolve an important data question in RA. Efforts such as these are necessary to ensure that any smartphone data that patients share with their doctors will not exacerbate clinician information overload, but actually facilitate clinical decisions.[10]

5B. Revising medication instructions in light of cognitive science makes them easier to follow

- **Adapting EHR-Based Medication Instructions to Comply with Plain Language Guidance—A Randomized Experiment.** The revisions were associated with an 8 percentage point increase in correct answers overall (from 55% to 63%, $p < 0.001$), although revisions were not equally effective for all instructions. Health literacy and health numeracy were strong and independent predictors of comprehension. Overall, mistakes on comprehension questions were common, with respondents missing an average of 41% (6.1 of 15) of questions. In this experimental study, a relatively simple intervention of revising text was associated with a modest reduction in frequency of misinterpretations of medication instructions. As a supplement to more intensive high-touch interventions, revising electronic health record output to replace complex language with patient-centered language in an automated fashion is a potentially scalable solution that could reduce medication administration errors by parents.[11]

5C. Post-surgical patients welcome a brief patient-reported outcome (PRO) follow-up

- **Informing, Reassuring, or Alarming? Balancing Patient Needs in the Development of a Postsurgical Symptom Reporting System in Cancer** After ambulatory surgeries, patients who recover at home have multiple questions about wound healing, symptoms and medication side

effects, and recovery expectations. We conducted user testing and rapid application development of a newly developed symptom reporting system that supports home-based recovery by inviting patients to self-report symptoms in the days after surgery and then receive an immediate feedback report giving context for their reported symptoms. Findings showed that some participants primarily valued reassurance, whereas others prioritized receiving alerts about potential problems. Results also showed that most patients wanted feedback framed as comparing their progress to their expected progress, not to that of other patients. The final feedback report provided patients with actionable recommendations, small graphs showing their progress, and with short "gist" text interpretations. The system has been implemented, and recruitment is ongoing for a large clinical trial of its effectiveness for reducing adverse events and unnecessary emergency or urgent care visits.[12]

5D. Public opinion is evolving in terms of attitudes toward health information technology
- The proportion of New Yorkers who reported using a personal health record rose consistently from 10% in 2012 to 27% in 2015.[13]
- People also became more likely to report that their doctor used in electronic health record, and those whose doctors used EHRs will more likely to have positive perceptions of EHRs.[14]

5E. Privacy policies are ambiguous and inconsistent for adolescents accessing their medical records
- **Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process.** Medical privacy policies, which are clear-cut for adults and young children, become ambiguous during adolescence. Yet medical organizations must establish unambiguous rules about patient and parental access to electronic patient portals. We conducted a national interview study to characterize the diversity in adolescent portal policies across a range of institutions and determine the factors influencing decisions about these policies. Within a sampling framework that ensured diversity of geography and medical organization type, we used purposive and snowball sampling to identify key informants. Semi-structured interviews were conducted and analyzed with inductive thematic analysis, followed by a member check. We interviewed informants from 25 medical organizations. Policies established different degrees of adolescent access (from none to partial to complete), access ages (from 10 to 18 years), degrees of parental access, and types of information considered sensitive. Federal and state law did not dominate policy decisions. Other factors in the decision process were: technology capabilities; differing patient population needs; resources; community expectations; balance between information access and privacy; balance between promoting autonomy and promoting family shared decision-making; and tension between teen privacy and parental preferences. Some informants believed that clearer standards would simplify policy-making; others worried that standards could restrict high-quality polices. Conclusions: In the absence of universally accepted standards, medical organizations typically undergo an arduous decision-making process to develop teen portal policies, weighing legal, economic, social, clinical, and technological factors. As a result, portal access policies are highly inconsistent across the United States and within individual states.[16]

- **Should parents see their teen's medical record? Asking about the effect on adolescent–doctor communication changes attitudes** Parents routinely access young children's medical records, but medical societies strongly recommend confidential care during adolescence, and most medical centers restrict parental records access during the teen years. We sought to assess public opinion about adolescent medical privacy. The Cornell National Social Survey (CNSS) is an annual nationwide public opinion survey. We added questions about a) whether parents should

be able to see their 16-year-old child's medical record, and b) whether teens would avoid discussing sensitive issues (sex, alcohol) with doctors if parents could see the record. Hypothesizing that highlighting the rationale for adolescent privacy would change opinions, we conducted an experiment by randomizing question order. Most respondents (83.0%) believed that an adolescent would be less likely to discuss sensitive issues with doctors with parental medical record access; responses did not differ by question order (P ¼ .29). Most also believed that parents should have access to teens' records, but support for parental access fell from 77% to 69% among those asked the teen withholding question first (P ¼ .01). Conclusions: Although medical societies recommend confidential care for adolescents, public opinion is largely in favor of parental access. A brief "nudge," asking whether parental access might harm adolescent–doctor communication, increased acceptance of adolescent confidentiality, and could be part of a strategy to prepare parents for electronic patient portal policies that medical centers impose at the beginning of adolescence.[17]

Invited papers and commentaries

6A. The PI was invited to provide an expert commentary on health information technology by JGIM.[19]

6B. The PI was invited to participate in a multinational collaboration developing a paper on common issues of patient access to personal medical data in different countries.[20]

6C. The PI was invited to coedit a textbook on consumer health informatics[21] and contribute a chapter on health literacy and patient technology.[22]

6D. The PI gave an invited presentation to the Institute of Medicine Roundtable on Health Literacy on communicating clearly with patients in the era of precision medicine.[23]

7. LIST OF PUBLICATIONS AND PRODUCTS

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