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Turning Data Into Information: Opportunities to Advance Rehabilitation Quality, Research, and Policy

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Abstract

Attention to health care quality and safety has increased dramatically. The internal focus of an organization is not without influence from external policy and research findings. Compared with other specialties, efforts to align and advance rehabilitation research, practice, and policy using electronic health record data are in the early stages. This special communication defines quality, applies the dimensions of quality to rehabilitation, and illustrates the feasibility and utility of electronic health record data for research on rehabilitation care quality and outcomes. Using data generated at the point of care provides the greatest opportunity for improving the quality of health care, producing generalizable evidence to inform policy and practice, and ultimately benefiting the health of the populations served.

Keywords

Electronic health records; Health policy; Health services research; Rehabilitation; Quality of health care

Over the past 2 decades, health care quality and safety have risen to the forefront of health policy and research. Landmark reports such as the 2001 Institute of Medicine's *Crossing the Quality Chasm*, together with the National Quality Strategy a decade later, aligned hundreds of organizations, individuals, and stakeholders toward 3 national aims: improved health, higher-quality care, and affordable care.^{1,2} Despite national support of these 3 aims,

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advances in rehabilitation practice, policy, and research are not in harmony. Policies are established without adequate empirical evidence and yet are directing changes in practice.³ Many clinical guidelines lack sufficient evidence.⁴ Quality improvement at the service level is not always disseminated or designed to be generalizable.⁵ Research is said to take a decade or more to be implemented,⁶ and that which is implemented in many cases cannot be measured or monitored for population-level health benefit. In this special communication, we define quality, apply the dimensions of quality to rehabilitation, and describe the “untapped potential” of electronic health record (EHR) data used to guide local quality improvements that can also be optimized to generate real-world evidence and to inform policy. Then we illustrate this untapped potential with a case example. We describe an in-depth evaluation of the feasibility and utility of using EHR data for stroke rehabilitation research in a multisite collaborative network. Use of data generated at the point of care provides the greatest opportunity for improving the quality of health care, producing generalizable evidence to inform policy and practice, and ultimately benefiting the health of the populations we serve.

Dimensions of quality: Priorities in rehabilitation

Greater attention to improving the health delivery system is useful when all involved have the same end goal. To improve the quality of care and improve the long-term outcomes of populations served, health delivery organizations, including those that provide rehabilitation services, refocused in 2001 to improve 6 dimensions of health care. Care needs to be *equitable, patient-centered, effective, safe, timely, and efficient*.¹ Applied to rehabilitation (table 1), these dimensions provide a clear action plan for measurement and improvement. Providers of rehabilitation care have some of the richest and most contextual information regarding patients' health and functioning. These data are extremely valuable for each domain of quality. In many cases, however, their use is reserved to individual patients rather than populations. Consequently, learning across patients and subgroups is minimal and improvements in quality are limited. There is a tremendous opportunity in optimizing use of EHR data at the population level to improve quality, inform policy, and generate real-world evidence,⁷ particularly from rehabilitation services where the data are richest with measures of what matters most to patients.

Untapped potential of EHR rehabilitation data

The World Health Organization considers health information systems 1 of the 6 essential building blocks of high-functioning health systems.⁸ Health information technology in the United States was accelerated in 2009 with the creation of the Health Information Technology for Economic and Clinical Health Act.⁹ This legislation established milestones for implementation and stimulated the adoption of EHRs and supporting technology. EHR implementation was to support use of electronically captured data to improve health care quality, safety, and efficiency. To reach these goals for data use, implementation of EHRs requires its own plan-do-study-act process improvement cycles to maximize utility.¹⁰ No EHR is perfect from the start, nor can it meet the needs of all stakeholders. Although these goals for using electronic data at the point of care and to improve the health of populations

are slowly becoming reality, rehabilitation research and policy affecting rehabilitation makes little use of EHR data.

Several national practice-based research initiatives are leveraging EHR data across organizations under a unifying purpose. For example, the National Institutes of Health Health Care Systems Collaboratory was designed to engage health care systems to use clinical and operational data for pragmatic clinical trials in an effort to improve the efficiency, relevance, and generalizability of study findings.¹¹ Similarly, the Patient-Centered Outcomes Research Institute funded the National Patient-Centered Clinical Research Network with 33 partner networks.¹² Of these, 20 are patient-powered research networks, governed by patients and their partners, and 13 are clinical data research networks based in health care systems such as hospitals, integrated delivery systems, and federally qualified health centers. These collaborative data networks are important infrastructures that leverage clinical and research experts to address coding and standardization, privacy and proprietary considerations, quality, and access to already-collected data available from a variety of sources. Studies that evolve from these networks are more efficient than replicating studies in multiple locations and are likely to include more variations in treatment patterns and outcomes than would be available in any one data source or site. This means the results are more likely to be generalizable and more useful to patients and clinicians. However, few of these national networks have focused on postacute care services such as inpatient rehabilitation. Both of these transformational initiatives are built on collaborating partnerships; neither includes rehabilitation in its leadership or as a primary focus in any of its partner's projects. This is an area where rehabilitation providers, researchers, and consumers could become more involved.

The rehabilitation community has become more engaged with population-specific registries. The Spine Quality Outcomes Database created by the American Academy of Physical Medicine and Rehabilitation and American Association of Neurosurgical Surgeons, and the cardiovascular registries supported by the American College of Cardiology provide a platform for clinical, research, and policy expert collaboration. The data in these registries are used to examine the delivery and outcomes of care. The research generates the evidence needed to strengthen clinical practice guidelines and direct policy. Registries also allow participating organizations to compare the delivery of care and outcomes across members. Variation in care can be informative. For example, delays in the initiation of home-based therapy may signal several areas of access for further investigation. High-performing organizations can be invited to share strategies. The common data framework standardizes the language of data being used to measure and monitor population-based improvements over time. These are several of the benefits to participating in registries. There are also some disadvantages. For rehabilitation providers, population-based registries dissect the total population of patients served, meaning that the advantages of participating in the registry are applicable to only a select segment of patients. It is also difficult to measure improvements when testing or spreading one strategy or intervention to other populations. This can be as simple as a new piece of equipment or as a complex as a care pathway. Different data networks and registries serve different purposes for different people.

EHR readiness for rehabilitation research network use: Case example

Leveraging EHR data across organizations opens a new space for health services research, including rehabilitation-focused pragmatic clinical trials and implementation research.¹³ The only rehabilitation-specific quality database in the United States that integrates clinical data from different organizations is the Exchanged Quality Data for Rehabilitation (EQUADR) network. EQUADR is accredited by the Agency for Healthcare Research and Quality as a patient safety organization (PSO). This federal PSO accreditation is reserved for organizations whose primary mission and function are to improve patient safety and health care quality.¹⁴ The EQUADR network supports member inpatient rehabilitation facilities and units to securely submit data to compare performance with similar rehabilitation programs, share best practices among members, and receive guidance for reducing risks and improving quality. These benefits of participating are common to all accredited PSOs (85 in 2017) and other nonfederal regional or national quality improvement organizations and initiatives with a shared and secure data infrastructure.¹⁵ Unlike quality networks for other services and specialties, clinical rehabilitation is in its infancy for bridging the divide between using EHR data for quality improvement at the local level and research on health care quality that can be broadly generalizable. Given the experience of EQUADR in establishing agreements across organizations, integrating data across rehabilitation programs, and standardizing data collection to meet external requirements for quality reporting, we recognized the potential of EHRs for research but were unclear of the limitations.

Approach

With stroke as our target patient population, our goal was to establish the foundation for a collaborative research network. We first established an invested team of health care providers, researchers, analysts, programmers, health care administrators, and committed key informants on billing, coding, and regulatory requirements across 4 rehabilitation facilities and 2 academic health systems in the United States. We planned for an in-depth evaluation of the ability to use EHR data for research. Guided by the Centers for Disease Control and Prevention's Evaluation Framework,¹⁶ we assessed the feasibility and utility of electronically stored clinical data for multisite studies of stroke patients who received inpatient rehabilitation. All efforts for the assessments of feasibility and utility were in-kind. The institutions' institutional review boards approved all activities with applicable data-sharing agreements. Our findings are not extrapolated to the use of medical record data from other countries as the review of global electronic health data policies and infrastructure is expansive and important to more fully explore as its own special communication.

Feasibility assessment of EHRs for rehabilitation research

Currently health care providers enter data into their EHR for clinical purposes, not for research purposes. Our feasibility evaluation was to determine whether EHR data could be realistically used for research. To do this we fully explored the EHR and focused on 3 elements of data used: data source format, data field types, and exportability and the intersection between them (table 2). This analysis indicated a significant amount of valuable

data is less likely to be used for quality or research because of how the information is stored, the limitations for exportability, and the variation across providers in how and how often unstructured data are provided.

In addition to EHR data for the participating rehabilitation programs, we also identified relevant data in additional data sources. These included web-based registries and locally maintained spreadsheets (e.g., Excel documents); neither are summarized here but their application to research is important to note. Excel documents often include data being considered or already ruled out for inclusion in EHRs. Evaluation of these data across partnering organizations could reveal variables less common in clinical practice but particularly valuable for certain patient subgroups or rare conditions. Testing data collection in a separate spreadsheet can be useful for determining more specifically what, how, when, and by whom the data should be collected. These pilot experiences can be useful but for data security should ultimately inform development for inclusion in EHRs. On the other hand, web-based registries already include an agreed-upon set of data. These are either manually populated or have electronic data transferred from EHRs to the registry. As already mentioned with the example in cardiovascular care, rehabilitation quality networks could evolve to (1) obtain broader agreement on common data elements useful for quality and research, (2) serve the needs of internal quality improvement, and (3) contribute to empirical evidence for clinical care.

Utility assessment of EHRs for rehabilitation research

Assessing utility means determining if the EHR information can meet the research needs. Research questions are needed to achieve this. The group began with a broad approach: to examine the care provided, the patient characteristics of those cared for, and their functional and community participation outcomes. A variable list was generated, with variables organized by the setting from which they would be available: prestroke variables collected on hospital admission, stroke characteristics documented in the acute hospital stay, patient factors documented during the inpatient rehabilitation stay, and variables documented after discharge. We also categorized variables such as patient sociodemographics, clinical, or administrative (e.g., admit date, until, length of stay). Utility was examined at the variable level. Two areas assessed included data hierarchy and variable availability versus specificity.

Variable availability and specificity

The overarching research question and an initial list of potential study aims led to a “wish list” of data the team wanted to obtain. The team tested and retested each variable’s availability via multiple team discussions, engagement of health system quality, informatics and research experts, and manual explorations of patients’ records. Exploration of the different components of storing the EHR data revealed various levels of variable availability and specificity (fig 1). Variation in completeness can be addressed in prospective data collection efforts. Data that are consistently available in a format inaccessible without review of narrative notes (e.g., stroke location in the admitting physician’s notes) create an obstacle for which a retrieval plan is needed.

Data hierarchy

Several variables were documented by more than one discipline in more than one location and at different times during the inpatient stay. It was important for the group to agree on the primary source of information (which provider or patient/family self-report) and the timing of documentation relative to admission, treatment, time of day, or discharge. The team considered it important to recognize the expertise of the discipline providing the information. For example, seeking to determine which stroke patients have spatial neglect on admission to a rehabilitation program was documented in 3 locations. Our group agreed on the following hierarchy; the highest and first source was the occupational therapist's admission assessment as it would have included standardized assessment tools for neglect common across therapists and likely also across institutions beyond our group¹⁷; second was the neurologic examination in the occupational therapy assessment and plan; and third was the physiatrist's history and physical on admission. If the information was not found in these 3 sources, then we would default to "not documented" (analyzed as no presence of neglect on admission).

EHR data quality

These examples illustrate that although data of interest are available in EHRs, electronic algorithms for data mining and manual data extraction may be needed to obtain what is available, and implementation of a new structure or protocol may be needed to ensure uniform data collection for each patient. These requirements are similar to what is often needed for participation in registries for quality improvement; however, participation in research collaborative networks with prospective data collection should allow variable-level input from participating sites. Evaluating the utility of EHR data required discussion of each variable of interest. Evaluating data quality must also be done at the variable level. With consensus on purpose, infrastructure, and use, network-level assessments of data quality and completeness could guide local improvements. This approach ensures that reports on quality and research findings are accurate, valid, and reliable. For this case example, internal funding was obtained from the 2 academic health systems to prepare the dataset for research use before applications for federal research funding.

Conclusions

Establishing a rehabilitation network of clinicians, rehabilitation service providers, staff, administrators, consumers, and researchers for the use of EHRs to collectively improve rehabilitation care quality can create real-world evidence underpinned by a common data model. Successes by groups such as the National Patient-Centered Clinical Research Network demonstrate that early investment in designing, developing, testing, and strengthening of the infrastructure and functionality of a research network established with clinical data can advance the science guiding practice and later expand to also include data contributed by patients. In conclusion, unless rehabilitation research on health care quality is relevant to rehabilitation service providers and their patients and is designed to use the data they collect, the evidence generated is likely to be dismissed. Embedding rehabilitation

research in real-world practice using data from EHRs is needed to inform policy and improve the quality of care worldwide.

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List of abbreviations:

EHR	electronic health record
EQUADR	Exchanged Quality Data for Rehabilitation
PSO	patient safety organization

References

1. Institute of Medicine (U.S.), Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st century Washington (DC): National Academy Press; 2001.
2. McKinney M First, do no harm. HHS' National Quality Strategy uses broad approach to communicate expectations to providers. *Mod Healthc* 2011;41:6–7.
3. Shrank WH, Saunders RS, McClellan M. Better evidence to guide payment reforms: recognizing the importance of perspective. *JAMA* 2017;317:805–6. [PubMed: 28245330]
4. Barnett AS, Lewis WR, Field ME, et al. Quality of evidence underlying the American Heart Association/American College of Cardiology/Heart Rhythm Society guidelines on the management of atrial fibrillation. *JAMA Cardiol* 2017;2:319–23. [PubMed: 28002833]
5. Baily MA, Bottrell M, Lynn J, Jennings B. The ethics of using QI methods to improve health care quality and safety Garrison, NY: Hastings Center; 2006.
6. Morris ZS, Wooding S, Grant J. The answer is 17 years, what is the question: understanding time lags in translational research. *J R Soc Med* 2011;104:510–20. [PubMed: 22179294]
7. Middleton B, Bloomrosen M, Dente MA, et al. Enhancing patient safety and quality of care by improving the usability of electronic health record systems: recommendations from AMIA. *J Am Med Inform Assoc* 2013;20(e1):e2–8. [PubMed: 23355463]
8. World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies Geneva, Switzerland: World Health Organization Document Production Services; 2010.
9. Office of the Secretary, Health and Human Services. HIPAA administrative simplification: enforcement. Interim final rule; request for comments. *Fed Regist* 2009;74:56123–31. [PubMed: 20166275]
10. Robertson A, Cresswell K, Takian A, et al. Implementation and adoption of nationwide electronic health records in secondary care in England: qualitative analysis of interim results from a prospective national evaluation. *BMJ* 2010;341:c4564. [PubMed: 20813822]
11. Richesson RL, Hammond WE, Nahm M, et al. Electronic health records based phenotyping in next-generation clinical trials: a perspective from the NIH Health Care Systems Collaboratory. *J Am Med Inform Assoc* 2013;20:e226–31. [PubMed: 23956018]
12. Fleurence RL, Curtis LH, Califf RM, et al. Launching PCORnet, a national patient-centered clinical research network. *J Am Med Inform Assoc* 2014;21:578–82. [PubMed: 24821743]
13. Graham JE, Middleton JA, Mallinson T, et al. Health services research in rehabilitation and disability the time is now. *Arch Phys Med Rehabil* 2018;99:198–203. [PubMed: 28782540]
14. Clancy CM. New patient safety organizations can help health providers learn from and reduce patient safety events. *J Patient Saf* 2009; 5:1–2. [PubMed: 19920431]

15. Elkin PL, Johnson HC, Callahan MR, Classen DC. Improving patient safety reporting with the common formats: common data representation for patient safety organizations. *J Biomed Inform* 2016;64:116–21. [PubMed: 27693764]
16. Centers for Disease Control and Prevention. Framework for program evaluation in public health. *MMWR Recomm Rep* 1999;48(RR-11):1–58.
17. Menon-Nair A, Korner-Bitensky N, Ogourtsova T. Occupational therapists' identification, assessment, and treatment of unilateral spatial neglect during stroke rehabilitation in Canada. *Stroke* 2007;38:2556–62. [PubMed: 17673707]

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Fig 1.
Example of variable availability and specificity.

Table 1

Quality defined and applied to rehabilitation

Quality	Application to Rehabilitation
Equity	Reducing the burden of illness, injury, and disability to all patients without bias or exclusion, particularly with regard to patients with speech and cognitive limitations or dependent on others for any activity of daily living
Patient-centeredness	Introducing methods to better inform and involve patients and their families in the care provided and decisions made. Ensuring accurate information follows the patient through transitions in care, across rehabilitation providers and settings, until return to the community. Promoting effective communication and coordination across care settings, including when patients transition from active care to management by primary care (general practitioner). Most recent functional assessment should be sent to primary care to enable longitudinal monitoring. Care plan used concurrent with care, addressing all domains of health and integrating communities and health systems for an environment that supports improved quality of life.
Effectiveness	Systematic use of evidence-based practice guidelines for diagnostic tests, assessments, intervention, and therapy to avoid both underuse of effective care and overuse of ineffective care. Evidence-based practice for any discipline where empirical evidence is lacking requires provider-patient partnerships to balance clinical expertise with patient and caregiver preferences and values.
Safety	Raising standards of care to ensure the appropriate action is taken with all eligible patients and harm is reduced.
Timeliness	Reducing delays to necessary treatment to maximize treatment benefit
Efficiency	Providing the right care to the right patients for the best value (through improved documentation of care and reduced medical errors, duplicative data entry, sampling for measurement, and ineffective overuse).

Table 2

Feasibility of EHR data for rehabilitation research

Types of Data	Examples	Use for Research	Exportability
Administrative	Encounters or costs, populated from other internal systems	Better than claims data because they includes all payers; best for measuring efficiency and timeliness of care	Personnel support for data set customization and interpretation
Patient status or provision of care as standard checkboxes; or yes, no, not documented	Elements of care pathways that may generate an action such as consult for neuropsychiatry; use of assistive device or screen completed	Depending on EHR development, can be used to assess performance against clinical guidelines	Personnel support to export
Measurement as standardized discrete data	Vital signs and lab values often requiring manual entry but data field format is predetermined or validated against a preset rule	Can be used to set or assess patient eligibility, disparities, level of risk, and responsive to treatment	Personnel support to export
Medications	Prescription, medication type, name, dose, timing administered, changes	Compared with claims data, EHR data provides more clinical detail on care and health status	Personnel support to export
Short text box (limited characters free text)	Comment boxes associated with routine status checks	Provides context but sometimes too much variability across patient population for use	Manual chart abstraction or electronic text mining needed
Free text narrative notes	Nursing, therapy, and physician progress notes and structured notes	Review indicated valuable information on complications, sequelae, and outcomes from standardized functional assessments. Data format revisions needed for standardization.	Manual chart abstraction or electronic text mining needed
Uploaded PDFs	Preadmission assessments and patient- reported outcomes	Without integrated data networks, these data are critical for longitudinal studies.	Manual chart abstraction or electronic text mining needed

Abbreviation: PDFs, portable document format.