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SPECIAL COMMUNICATION

Advancing the Implementation of Patient-Centered Outcomes in Rehabilitation Learning Health Systems: Insights From the 2024 LeaRRn Summit

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Abstract

Patient-centered outcomes can inform the delivery of value-based rehabilitation care; however, there are many barriers that affect their routine use in clinical care. Learning health systems—which focus on improving patient-centered outcomes through the iterative process of data collection, knowledge generation, and practice change—are well-positioned to overcome these barriers. In September 2024, the Learning Health Systems Rehabilitation Research Network and the Center on Health Services Training and Research hosted the *Power of Patient-Centered Outcomes in Rehabilitation Learning Health Systems Summit*. The Summit aimed to advance the science and practice of implementing patient-centered outcomes in learning health systems. It was organized around the following 5 stages of the patient-centered outcome lifecycle in learning health systems: (1) selecting measures, (2) capturing data, (3) accessing data, (4) analyzing data, and (5) using data. At the Summit, experts across the rehabilitation community presented current work related to each of these lifecycle stages, discussed challenges to implementing patient-centered outcomes in learning health systems during breakout groups, and generated potential solutions for improving implementation of patient-centered outcomes across the 5 stages. The purpose of this paper is to disseminate the central themes of the Summit, which include common challenges and potential solutions to implementing patient-centered outcomes in rehabilitation learning health systems. In doing so, this paper aims to serve as a catalyst for future efforts to incorporate patient-centered outcomes within learning health systems in rehabilitation care.

List of abbreviations: EHR, electronic health record; LeaRRn, Learning Health Systems Rehabilitation Research Network; LHS, learning health system

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The United States spends twice as much per person each year on health care compared with other high-income countries, yet we consistently obtain worse health outcomes (eg, shorter life expectancy and lower quality of life).[1-3] This necessitates a shift toward value-based health care, where meaningful patient outcomes are improved while lowering the costs associated with these outcomes (ie, better outcomes per dollar spent).[4-6] Traditionally, improving the value of health care has focused on lowering costs; however, achieving better outcomes is central to value-based care. Specifically, the outcomes measured must be meaningful to patients,[4] making patient-centered outcomes (eg, pain, function, and quality of life) uniquely important when addressing the value of health care.[7] Many efforts to date have primarily focused on health system−centered outcomes (eg, hospital readmissions) rather than patient-centered outcomes.[8,9] However, the former often represent aspects of utilization (eg, length of stay), which may be better positioned as process metrics versus outcomes, or the absence of adverse events (eg, decreased infection rates). In contrast, patient-centered outcomes reflect key aspects of health that are relevant and important to patients with the opportunity to be targets of high value care and, when optimized, can reduce the individual and societal burden of illness and longer-term, downstream spending. These types of outcomes are especially key for rehabilitation services, given the focus on function. More broadly, payors such as the Centers for Medicare and Medicaid Services are increasingly focusing on patient-centered outcomes (eg, patient-reported outcome-based performance measures of pain or function) for quality and payment in recognition of their role in value-based care.[10-12]

The implementation of patient-centered outcomes within health care systems, including by rehabilitation providers, is highly variable[13-15] because of barriers that affect routine use in clinical care. These barriers include limited knowledge about selecting patient-centered outcomes, unclear processes for collecting these measures, and uncertainty in interpreting and returning the results to clinical teams in ways that can directly improve clinical care.[16-18] Learning health systems (LHS)—systems that generate new knowledge from clinical practice and then implement this knowledge back into clinical practice—are uniquely positioned to overcome the barriers to implementing patient-centered outcomes in clinical practice.[19-23] The LHS typically use an iterative process of data collection, knowledge generation, and practice change, bringing together expertise from clinicians, health system leadership, researchers, and informaticians into learning communities. These expert learning communities have a vested interest in improving health outcomes, and because they need patient-centered outcomes to engage in patient-centered data-driven care, they have a unique opportunity to devise solutions to promote the uptake of patient-centered outcomes within their LHS.[24,25]

Within an LHS, rehabilitation community members may be key champions in the implementation of patient-centered outcomes. First, patient-centered outcomes are key targets of rehabilitation services across the care continuum, from acute care to the community, making widespread collection and use of such outcomes essential for an LHS focused on improving rehabilitation care processes and outcomes.[26,27] Simultaneously, the rehabilitation community brings expertise in patient-centered outcomes, such as the focus on function, that can advance broader interdisciplinary LHS efforts to improve value for patients and systems that extend beyond rehabilitation services themselves. Additionally, such broader efforts offer opportunities to further improve patient management through communication of patient-centered outcome data to other invested partners before and after traditional rehabilitation services (eg, pre-episode function and post-episode return to work status).

In September 2024, the Learning Health Systems Rehabilitation Research Network (LeaRRn) and the Center on Health Services Training and Research hosted the *Power of Patient-Centered Outcomes in Rehabilitation Learning Health Systems Summit* (hereafter referred to as the Summit). Recognizing the rehabilitation community's unique role in the implementation of patient-centered outcomes in an LHS, the Summit aimed to advance the rehabilitation-related science and practice. The Summit took a comprehensive approach by addressing the entire implementation lifecycle of patient-centered outcomes within an LHS. The Summit was organized around the following 5 stages of the implementation lifecycle: (1) selecting measures; (2) capturing data; (3) accessing data; (4) analyzing data; and (5) using data. Experts across the rehabilitation community attended the Summit to (1) present current work related to each of these stages; (2) convene breakout groups to identify challenges related to each of the lifecycle stages; and (3) generate potential solutions for improving the implementation of patient-centered outcomes at each of the 5 lifecycle stages. The purpose of this article is to disseminate the central themes of the Summit, including common challenges and promising solutions to advance the implementation of patient-centered outcomes in rehabilitation LHS.

Description of the summit

Summit format and attendees

The Summit employed a hybrid format with in-person and virtual components to stimulate deep discussions, facilitate networking opportunities, and foster broad information sharing and participation among attendees. In-person attendees (n=85) were nominated by the Summit Planning Committee (ie, a team comprising LeaRRn leadership and clinical researchers representing rehabilitation allied health disciplines) and were selected to represent the diversity needed within learning communities to successfully implement patient-centered outcomes in LHS. They included LeaRRn and Center on Health Services Training and Research trainees, health system representatives (clinicians, researchers, informaticians, and operational leaders in rehabilitation), experts in the field, and persons with lived experience. Virtual attendance was open to the public and free to attend.

Panel presentations

The Summit included 5 panel sessions, each of which had 4 speakers who were conducting innovative work in their respective LHS. The 5 panel sessions were organized to address the entire lifecycle of patient-centered outcomes within an LHS (table 1). Each panel included formal presentations and concluded with moderated questions and discussion. The Summit Planning Committee assigned individuals from the in-person audience to serve as "synthesizers" of content, discussion, and comments from each session. To efficiently obtain input from all willing attendees throughout the Summit, audience members were asked to provide comments and questions on sticky notes placed on session-specific poster boards (in-person participants) and through the chat feature of Zoom (virtual participants).

Table 1 Sessions of the summit that align with the lifecycle of patient-centered outcomes in a rehabilitation learning health system.

Session Title	Panel Presentation Titles and Speakers	Session Moderator	Purpose of the Session
Selecting measures	1. *Enabling Use of Patient-Centered Outcomes and Clinical Data for Patient-centered CER*: Erin Holve, PhD, MPP, MPH and Nikolas Koscielniak, MS, MPH, PhD 2. *Balancing Stakeholder Needs in Selecting and Collecting Outcome Measures:* Chloe Slocum, MD, MPH 3. *Engaging Clinicians in Measure Selection:* Claire Kalpakjian, PhD, MS	Lisa Juckett, OT, PhD	Participants will understand how to use tangible tools and resources when engaging stakeholders in outcome measure selection.
Capturing data	1. *Implementing Measurement of Patient Function in the Acute Hospital:* Daniel Young, PT, DPT, PhD 2. *Capture of Standardized Performance-Based Outcomes in Inpatient Rehabilitation:* Julia Carpenter, MA, CCC-SLP 3. *Delivering Care in the Home (a highly regulated, value-based payment setting):* Michael Johnson, PhD, PT 4. *Outcome Capture in Outpatient Clinics:* Stephen Hunter, PT, DPT, OCS, FAPTA	Jason Beneciuk, PT, DPT, PhD, MPH	Participants will understand a variety of approaches to address stakeholder priorities, needs and workflow when collecting patient-centered outcomes.
Accessing data	1. *Integrating Data from Multiple EMRs to Enhance a Learning Health System:* Mindi Manes, PhD 2. *Integration of Patient Reported Outcome Measures (PROMS) that Utilize Computer Adaptive Testing (CAT) to Improve Patient Engagement and Quality of Care:* Timothy Marshall, PhD, MHA, MS 3. *Outcomes Systems. . .Are we just Pedaling in Outcomes, or Revving the Engine towards Value-Based Care?:* J. Leigh Harris, PT, DPT 4. *Establishing a Data Repository for Precision Rehabilitation:* Ryan Roemmich, PhD	Maggie French, PT, DPT, PhD	The purpose of this session is to describe a range of infrastructure approaches used by learning health systems to store and access patient-centered outcomes data.
Analyzing data	1. *Introduction and Overview of Analytic Approaches:* Linda Resnik, PT, PhD 2. *Descriptive / Explanatory Analytics:* David Kohns, DO 3. *The Role of Patient-Centered Outcomes in Predictive Analytics:* Maggie Horn, DPT, MPH, PhD 4. *Prescriptive Analytics in Stroke Rehabilitation:* Allan Kozlowski, PhD	Claire Kalpakjian, PhD, MS	The purpose of this session is to highlight major types of analyses that can be performed using patient-centered outcomes data and discuss ways to enhance rigor and validity.
Using data	1. *Use of Patient-Centered Outcomes at an Organization Level:* Mary Stilphen, PT, DPT 2. *Using Data to Identify Areas for Practice Improvement:* Jason Beneciuk, PT, DPT, PhD, MPH 3. *Using Data at the Clinician Level: Design and Implementation of the "PT-PENCIL":* Joshua Johnson, PT, DPT, PhD 4. *Using Data to Inform Patient-Centered Decision-Making:* Patricia Grady-Dominguez, PhD, OT	Brocha Stern, PhD, OTR	Participants will be able to describe how data can be used to address the interests of diverse groups of stakeholders.

Breakout groups

The culminating 90-minute breakout groups (in-person attendees only) were used to further discuss the key information and ideas presented in the panel presentation sessions, as well as questions that arose from them. The objective of the breakout groups was to identify next steps within each lifecycle stage to move the field forward. Each in-person attendee participated in a single self-selected breakout group. There were 4 breakout groups, as the topics of capturing and accessing data were combined into a single group. The breakout groups were moderated by the same individual(s) who moderated the panel session for that topic. The moderators used notes from the synthesizers and attendee comments from the poster boards to focus the discussion of the breakout groups. Each breakout group had a "recorder" who took detailed notes of the discussion, which was also audio-recorded. During the final session of the Summit, the in-person audience reconvened, and breakout group moderators reported on the discussion that occurred within their group and focused on addressing the following questions: (1) what is the current state of the science and practice related to patient-centered outcomes? (2) what are examples of successful practices related to patient-centered outcomes? (3) what are the challenges or barriers related to successful execution of the specific lifecycle stages? and (4) what are potential opportunities to address the identified challenges?

The subsequent portions of this article summarize discussions from each breakout group. Although the Summit and the information below are organized by the specific lifecycle stage, we acknowledge that the stages are interrelated and inherently tied to one another. Therefore, some overlap in the challenges and opportunities for each of these stages is expected. This overlap highlights the need to carefully consider each stage to maximize the success of efforts to implement patient-centered outcomes in LHS.

Selecting tools to measure patient-centered outcomes

The members of the selecting measures breakout group identified several facilitators that support the selection of tools to measure patient-centered outcomes. These facilitators include an increasing focus of clinicians and health systems on exploring how outcome measures influence care, strategies to share data with both patients and care partners, as well as existing resources for selecting tools that measure patient-centered outcomes, such as the hundreds of measures described on RehabMeasures.org.[28] Group members also noted the importance of selecting measures with sound psychometric properties (eg, reliability, validity, responsiveness) for research and practice, as well incorporating didactics on the appraisal of tools to measure patient-centered outcomes within professional rehabilitation program curriculums (eg, OTD, MOT, DPT, MS-SLP, SLPD). Despite recognizing the value of patient-centered outcomes and enthusiasm surrounding their measurement, group members identified barriers that hinder effective tool selection in rehabilitation LHS (table 2). Here we will describe in more detail 2 primary barriers and opportunities identified during the group discussion.

One significant barrier is selecting patient-centered outcome measures that can be feasibly integrated into existing workflows and electronic health record (EHR) systems. This selection is challenging for several reasons. First, clinicians often face external pressures from administrators or policymakers to collect specific data that are not necessarily patient-centered, therefore making it difficult to integrate additional patient-centered measures into practice because of time constraints. Furthermore, once a measure is selected, the results must be routinely and accurately documented with minimal burden to the clinician. Without such documentation, data cannot be easily accessed and used to inform care delivery or address research questions.[29,30] Systematic documentation of patient-centered outcome measures requires clinic and system level efforts, in addition to the direct activities by the clinician and patient. These efforts must be considered when selecting tools to measure patient-centered outcomes. Partnerships with trained informaticians during the selection process are needed to ensure that the patient-centered outcome measures selected can be built into the EHR and clinical workflow. To ensure a productive partnership with informaticians, support from administrators and other leadership is essential, as changes to the EHR typically require buy-in from administration. In the future, technology may help overcome some of the challenges associated with documentation barriers. For example, natural language processing and artificial intelligence may be harnessed to analyze clinical notes and other data sources without a standard documentation format. However, this technology is still in its infancy, especially related to patient-centered outcomes.[31-33]

Another barrier is the limited involvement of patients and care partners (eg, family members) in the selection of patient-centered outcome measures. Involving patients and care partners in this process is challenging, given that they may lack adequate health literacy[34] or, understandably, may not have knowledge of specific measure priorities or psychometric properties to identify relevant patient-centered outcome measures. Others may have impairments in communication or cognitive-linguistic skills that may affect their full participation in discussions about the selection of outcome measurement tools. Furthermore, it remains unclear to what extent patients prioritize involvement in these decisions or whether they prefer to rely on clinicians and researchers to guide the outcome measure selection process. One opportunity to address this barrier is in using rigorous qualitative and mixed-methods research to inform outcome measure selection. Engaging patients, care partners, and other members of the learning community in this process—employing multimodal communication supports for these individuals, when necessary—can ensure that the measures chosen are relevant to their goals and meaningfully measure their participation in activities and other outcomes that are most important to them.[35] This research can also explore the extent to which patients and care partners wish to be involved in the selection process, providing insights into how to align patient preferences with clinical practices. Fostering patient and caregiver engagement through advisory boards, lived experience panels, and focus groups can amplify their voices in the outcome measure selection process.[36]

Capturing and accessing patient-centered outcomes

During the Summit, members of the capturing and accessing data breakout group acknowledged that systematically capturing patient-centered outcomes in a format that can be accessed (ie, discrete data rather than free text) is vitally important to enable analysis and use in clinical care. There was also broad consensus that optimal data capture requires collaboration within a learning community that includes patients, clinicians, informaticians, LHS researchers, and clinical, executive, and system leadership. Similarly, accessing data requires collaboration and input from the parties who need the data and individuals with expertise in data architecture and bioinformatics. Only when shareholders work together can the EHR be designed to facilitate data capture within existing clinical workflows and can the necessary parties access the data. Additionally, the processes and systems used to capture and access patient-centered outcomes must be aligned with priorities of all members of the learning community. For example, patients want to know how they are responding to care, clinicians want the data to guide their clinical decision making, and clinical leadership want to know if high value care is being delivered within their health system. The processes and systems used to capture and access data must meet these diverse, yet interconnected needs. To achieve high-quality, accessible, and actionable data, group members identified several barriers to developing processes to capture and access patient-centered outcomes, as well as potential opportunities to improve the ability of LHS to develop these processes (table 2). Here, we will discuss in more detail 3 primary barriers and opportunities that were identified during the group discussion.

One barrier identified was the demands on resources, both financial and time, needed to develop the systems and processes to

Table 2 Barriers and potential opportunities to selecting, capturing and accessing, analyzing, and using patient-centered outcomes in rehabilitation learning health systems.

Barriers	Potential Opportunities
Selecting measures	
Logistical feasibility	Use technology such as natural language processing and artificial intelligence to analyze clinical data, facilitating outcome measure integration
	Implement decision support tools to assist clinicians in selecting appropriate outcome measures
	Partner with trained informaticians to ensure that measures can be built into the electronic health record
Limited patient involvement	Foster patient and caregiver engagement through advisory boards, lived experience panels, and focus groups
	Engage patients and care partners through qualitative and mixed-methods to align measures with their goals
	Establish processes to assess patients' desired level of involvement
	Build trust by addressing health literacy gaps and involving stakeholders in decision-making
Cultural irrelevance of outcome measures	Select or develop adaptable and culturally relevant outcome measures, ensuring accurate translations and meaningful applicability
	Involve diverse populations in the development and selection process to ensure cultural and contextual appropriateness
Capturing and accessing data	
Challenges in establishing and sustaining culture	Involve all members of the learning community throughout the lifecycle of patient-centered outcomes to ensure adherence to data capture
	Empower all members of the learning community to use patient-centered outcomes to ask questions about clinical care and operations
	Empower all vested parties to review the data that align with their priorities
	Maintain communication between all vested parties throughout lifecycle of patient-centered outcomes
	Create an environment where data is valued and used
	Create an environment where data needs are defined bottom up and also aligned top down in order to best address competing priorities
	Create forums for vested parties to gather, discuss, and collaborate
Lack of standardization within and between health systems	Engage clinicians, make initial decisions, and start somewhere realizing this will be an interactive and iterative process
	Distinguish between "need to know" and "good to know" data that can be tailored for different settings
	Develop internal and external collaborative learning communities to promote widespread use of standard patient-centered measures
	Develop and leverage crosswalks (ie, tools that convert scores on one tool to scores on another)
	Identify ways to balance between capturing measures that are too broad and including every possible diagnosis specific measure
	Develop assessments that more comprehensively measure functional domains to limit number of measurements used
High financial costs and time demands of infrastructure to capture and access data	Develop and share processes and codes
	Leverage grant funding for specific projects to help build infrastructure
	Partner with electronic health record vendors to include discrete fields for patient-centered outcomes
	Optimize already available resources
	Leverage third-party systems and shared infrastructure (ie, vendors or PCORnet)
Rehabilitation value messaging	Emphasize rehabilitation value integrated as part of a health system to achieve higher priority (value beyond rehabilitation)
	Take advantage of administrative case reports to disseminate success stories and approaches
	Communicate that certain measures (eg, function) are relevant to all patients in the system, not just those receiving rehabilitation

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Table 2 (*Continued*)

Barriers	Potential Opportunities
Lack of transparency	Provide clear vision with respect to what will be done with collected data (eg, internal vs external benchmarking) Inform patients (consider use of scripting) about why data is being collected (eg, improve clinical practice, optimize care decision-making, enhance patient-clinician communication)
Analyzing data	
Collection of disparate measures	Build trust with key groups to improve completeness of data that are collected Use data from the lived environment and other data sources (eg "All of Us")
Statistical expertise and the need to balance rigorous analysis and efficiency for rapid implementation	Develop rehabilitation specific expertise in health informatics by both training clinicians in informatics and bringing informaticians into rehabilitation programs Teach clinicians and trainees how to use outcome measures for clinical care and integrate interpretation of more advanced analyses into clinical education Improve collaborations between health systems and academic researchers Increase training for embedded health system researchers Foster sustained relationships between health systems and academic medical centers given the time needed to develop and pursue health systems research Educate clinical and operational leadership about the research process and balance expectations Standardize common data elements to allow aggregation of data and/or study results across multiple health systems
Inherent challenges of using practice-based data to make causal inferences	Develop pragmatic trials that can be conducted in real-world practice Advance the use of quasi-experimental designs and more sophisticated causal inference techniques and study designs (eg, propensity score matching, target trial emulation) Make research methods transparent and reproducible by sharing methods (eg, codes, data elements) and approaches used and sharing data through repositories and clinical research networks Teach rehabilitation scientists how to use conceptual models/frameworks in data analyses
Potential harms resulting from analyses that do not consider case mix	Improve analytic skills related to health equity and justice and use appropriate methods to examine how models (such as predictive models) perform for different subgroups Ensure collection of social determinants of health data Consider social determinants of health in analyses
Using data	
Limited perceived value across stakeholders	Perform value-mapping exercises to identify points of alignment between health system, clinician, and patient values Strategically align efforts with health system, clinician, and patient values and priorities to accelerate implementation timelines Speak the language of each group's values (eg, "return on investment" for health system leadership) to facilitate buy-in Develop a toolkit to support local change agents in communicating the right message to the right people Find opportunities for small wins to get and retain a seat at the organizational decision-making table Develop a system culture of continuous improvement where both health system leaders and frontline clinicians recognize the need to consistently engage in cycles of assessment and adjustment to improve quality Include patients in learning communities to ensure their values and priorities are reflected
Lack of partnerships and trust between frontline clinicians and researchers	Identify clinician and departmental/organizational readiness to change and find common ground with targeted strategies to move forward in a collaborative manner Leverage peers (ie, "insiders") to educate clinicians and guide implementation efforts Provide feedback to clinicians in a timely manner on aggregate performance and/or at the point of care using clinical decision making tools Frame the use of patient-centered outcomes in direct patient care as supporting (shared) decision-making vs replacing clinician autonomy and expertise Frame performance on outcomes as an opportunity for growth vs a punitive approach Incorporate principles of patient-centered data-informed (shared) decision-making in the education of rehabilitation students

(*continued on next page*)

Table 2 (*Continued*)

Barriers	Potential Opportunities
Difficulty accessing, interpreting, and communicating outcomes	Make data easily accessible to the clinician (and patients) through dashboards and electronic health record alerts Use scoring metrics and guides that are interpretable to clinicians and patients Leverage visualizations to aid in score interpretation and communication Engage information technology teams to generate meaningful information from raw data Demonstrate and provide information on shared decision-making as a continuous process vs a one-time interaction Provide scripts as starting points for clinician-patient discussions of patient-centered outcomes
Potential for exacerbation of disparities and other unintended consequences	Create generalizable solutions to support using data as part of a learning health system that can be implemented out-of-the-box in lower-resource settings Thoughtfully consider adjustment for patient level social determinants of health when comparing patient-centered outcomes between clinicians and practices Continuously (re-)evaluate the effects of decision tools guided by patient-centered outcomes data to limit unintended consequences

capture and access these data. For example, developing the systems and processes to capture and access data often requires resources to design or reconfigure the EHR to capture and extract data to be used for subsequent analysis. These financial and time demands, which may disproportionately affect smaller health systems and under-resourced settings, may be prohibitive because of tight budgets and limited workforce capacity across health systems. The group members identified several potential opportunities to mitigate barriers associated with the high demand of sometimes potentially limited resources. These opportunities included developing shared codes and processes for capturing and accessing data. Although some health care systems have disseminated information on how they have established processes to capture and access patient-centered data,[26,37,38] there was agreement among participants that such efforts should be done more broadly to guide other health care systems embarking on this endeavor. There was also enthusiasm for the idea of rehabilitation leaders lobbying existing EHR vendors to facilitate the incorporation of discrete fields for important patient-centered outcomes to reduce the demands on resources for developing infrastructure to capture these data. Group members acknowledged that some vendors have already agreed upon standards for outcome measures or other discrete data and these efforts could be leveraged and optimized in the future.

This last potential opportunity related to resource demands requires that members of the learning community agree on the set of patient-centered outcomes that should be widely collected. Given that lack of standardization was identified as another primary barrier to systematically capturing and accessing patient-centered data, members of this breakout group agreed that there was a need for some minimum level of standardization of patient-centered outcomes within and between health systems through a set of common data elements (ie, agreed upon data elements that everyone collects). One specific challenge related to standardization was whether the common data elements should be specific to diagnosis, discipline, and setting or agnostic to those factors. This concern arose because there was concern about the ability to identify one single comprehensive or generic measure that could be used across diagnoses, disciplines, and settings. In general, there was a belief that a single, generic measure would not sufficiently address the needs of all members of the learning community, but that the level of specificity related to diagnoses, disciplines, and settings was an important one, given the implications it would have on the ability to combine data across health care systems. Despite this challenge, there was consensus for the need to engage rehabilitation providers and other health care professionals early in the process of identifying key patient-centered outcomes that would be systematically captured and accessed. This engagement could occur within a single health care system or across multiple systems, recognizing that achieving agreement across separate health systems would be challenging. Although ultimately standardization across systems would be ideal, group members agreed that standardization within single systems could potentially accelerate standardization between systems. For example, standard processes to capture and access data from orthopedic populations in one health system could inform development of similar, albeit not necessarily identical, processes for other health systems. Crosswalking methods that equate the scores of disparate measures that assess the same constructs[39-42] can then be employed to overcome variation in which tools are used to assess patient-centered outcomes, so that larger scale datasets generated from multiple health systems can be used to answer clinical questions.

A final barrier is the need for developing and sustaining a culture within the health care system that supports and values patient-centered outcomes. Furthermore, once this culture is developed, sustaining it amid staff turnover, shifting priorities, and waning enthusiasm as time passes can be particularly challenging. Frequently silos between members of the learning community limit the ability of systems to develop processes and systems to capture and access patient-centered data. For example, LHS researchers interested in capture, analysis, and interpretation of patient-centered outcomes data may not consider the effect this process may have on clinical workflow. As another example, rehabilitation providers (eg, physical therapists) acting in a silo may miss opportunities to communicate the value of patient-centered data with other health care professionals (eg, nursing). There was consensus that removing these silos and creating a culture that values teamwork, collaboration, and open communication between all members of the learning community was essential for successfully capturing and accessing high-quality patient-centered outcomes. Group members agreed that creating forums that encourage brainstorming, discussion, and collaboration within the learning community was essential. They also agreed that although some parties

may be more involved at different stages of the lifecycle (eg, clinicians and clinical teams in capturing data, informaticians in developing data infrastructure to access data), it was critical to include all members of the learning community at all stages of the lifecycle.

Analyzing patient-centered outcomes

During the analyzing data breakout group discussion, participants noted several opportunities to improve the analysis of patient-centered outcomes data within rehabilitation LHS and identified multiple barriers. Panel speakers provided examples of analyses used within their health systems to describe care outcomes (descriptive analytics), predict outcomes (predictive analytics), and guide care (prescriptive analytics). It was evident to audience members that substantial methodological expertise is needed to work with large, complex datasets to conduct the complex statistical analyses that were described. Group members identified facilitators that they believed would improve the analytic capacity within rehabilitation LHS. These include (1) development of rehabilitation specific informatics expertise; (2) increased and sustained partnerships between academic institutions and health systems with increasing opportunities for "embedded" researchers within health systems to enhance methodologic expertise; and (3) greater engagement of members of the learning community throughout the process to educate clinical and operational leadership about the research process. Other opportunities for improving analytics are detailed in table 2.

Barriers identified in the discussion include the collection of disparate measures, gaps in statistical expertise and adequate personnel to support analyses and related initiatives, limitations of using data from practice to make causal inferences, and the potential for analyses with poor internal or external validity. As in the breakout session on capturing and accessing data, the lack of standardization in measurement tools was a barrier discussed during this session. When considering this barrier during the analysis stage, the lack of standardization presents challenges in combining data across clinical settings, within a health care system, and across health systems. Most broadly, this hampers the ability to draw conclusions at the population level. This can also limit sample sizes because of missing data and limit the use of advanced statistical models requiring large samples. Additionally, inconsistent use of measures can contribute to contradictory or disparate findings in a clinical setting. For instance, the use of different scales to measure cognitive function can lead to discrepancies in interpreting patient progress and can hamper the ability to complete meta-analyses and large-scale studies. This lack of standardization also limits the ability to reproduce results from one system to another for 2 primary reasons. First, one system may not measure a given construct with the same tool as other systems and, second, the same measurement tool may be stored in different formats within different systems, making data not interoperable across systems. There are several opportunities to overcome these interrelated barriers and improve the reproducibility and interoperability of our analyses. The development of crosswalk systems that translate or map data from different measurement tools onto a common scale can facilitate comparisons across studies and settings.[43] This type of effort has been done for some measures, for example, mapping the AM-PAC to PROMIS.[40-42] Similarly, use of measurement tools that more comprehensively assess a construct, such as function, could minimize this barrier. One example of this is the Functional Balance Ability Measure, which aims to more completely measure balance compared with other tools.[44] Another potential solution is using common data models in which the same variable is stored in the same location within a standardized data structure and that variable is referred to with the same term.[45,46] Several common data models[46] are used in other fields of medicine (eg, OMOP[47], PCORnet[48]), but their use in rehabilitation has been limited to date.

Second, despite their crucial role, analysts are often lacking or unavailable in many health care systems. Lack of analytic expertise can result in overly simplistic analyses of complex health data. Moreover, collaboration between experts in analysis and rehabilitation care that is needed to produce evidence that truly informs clinical care often goes unrealized. Increasing the number of analysts within rehabilitation health systems will improve the quality of analyses that inform care, yet financial constraints often make this challenging. Additionally, there are few forums or opportunities for data analysts within rehabilitation LHS to share analytic approaches, analytic models, code, and other practices, which subsequently reinforces silos and hampers the progress of rehabilitation LHS. Platforms and forums to exchange methodologies, insights, and findings can foster collaboration, standardization, and best practices between analysts and with other members of the learning community. Development of best practices can improve the analyses performed using patient-centered outcomes.

A third primary consideration is the inherent challenge associated with using practice-based (ie, observational) data to make causal inferences. This may lead to analyses that are inaccurate or incomplete and may negatively affect subsequent clinical decision-making and care planning. Potential opportunities may begin with the standardization of common data elements to allow for the aggregation of greater volumes of data across multiple health systems. Identifying and expanding the use of specific study designs and methods that can improve the ability to draw causal conclusions from data within the rehabilitation LHS would be valuable. Examples include regression adjustment, use of propensity scores and inverse probability of treatment weighting,[49,50] instrumental variables,[51] and target trial emulation.[52] Training rehabilitation scientists to appraise the design and interpretation of these analytical approaches would increase the adaption of these analytical approaches and ensure the translation of the results in clinical care.

Finally, there are critical equity considerations in analyzing and interpreting the results of rehabilitation LHS data that compound the above mentioned pragmatic challenges. Outcomes data and the measures used to produce them may reflect systemic biases, such as the underrepresentation of certain demographic groups or socioeconomic disparities in access to care. These biases can lead to distorted conclusions that perpetuate inequities in rehabilitation care. Creating analytic frameworks around equity and disparities can help ensure best practices for analyzing rehabilitation data. For example, frameworks that include health equity concerns and social determinants of health are essential in creating a more inclusive analytic approach. Frameworks can help ensure that factors like socioeconomic status, race, and geographic location are consistently accounted for in analytic models and will also enable greater standardization than is currently practiced.

Using patient-centered outcomes to inform care

Members of the using data breakout group agreed that using patient-centered outcomes to inform care supports value-based rehabilitation services, with benefits for health systems, clinicians,

and patients. Examples of applications include health system leaders using aggregate data to guide practice improvement and clinician-patient dyads using data for personalized decision-making at the point of care.[53-55] Breakout group members advocated to use data to inform care as part of rehabilitation LHS, but acknowledged real-world constraints to address before this practice becomes widely adopted. Broadly, earlier segments of the implementation lifecycle of patient-centered outcomes (ie, selecting, capturing, accessing, and analyzing) need to be in place before data can be used in meaningful ways. Assuming the other stages have been well executed, barriers remain related to using patient-centered outcomes to inform clinical care. These barriers and potential opportunities for using patient-centered outcomes to inform care are presented in table 2, with several barriers and opportunities detailed below.

A barrier that was repeatedly brought up during the breakout session was limited perceived value for using such data across the learning community. Breakout group members noted that the use of patient-centered outcomes within an LHS should be targeted at delivering the most effective, efficient, and patient-centered care for the patient. However, how using patient-centered outcomes adds value to clinical care may not always be clear to all members of the learning community. Group members highlighted the need to find points of shared value between organizational leadership, frontline clinicians, and patients to align efforts to use data with those values, and to communicate between groups using value-concordant language. Intentionally aligning efforts with priority system challenges was also suggested to accelerate timelines related to the use of patient-centered outcomes. For example, using patient-centered outcomes to differentiate patients with or without priority needs for rehabilitation services can refine resource allocation, which offers a financial benefit for the system (ie, "return on investment"), allows busy clinicians to spend their limited time with patients who require skilled care, and allows patients to receive the care they need in a timely manner.[56-58] Group members noted that creating a system culture of continuous improvement, which fosters perceived value of using data to inform care, cannot be forced, especially from an external researcher. Genuine collaboration between academic partners and health system leaders and clinicians requires time and prolonged engagement to build mutual trust and respect. Overall, greater resistance to using patient-centered outcomes was perceived at the health system leader and clinician level versus at the patient level, with one group member noting that patients "love their data" in point of care conversations. However, participants still encouraged increasing engagement of patients in learning communities to ensure that their values are reflected in how outcomes are used at all levels of the health system.

A related barrier was lack of clinician engagement and trust, which group members noted would be partially addressed by providing timely and transparent return of data to frontline clinicians. Participants advocated for emphasizing to clinicians that patient-centered outcomes are intended to be starters for a conversation with a patient or for a decision-making process and are not intended to replace clinician autonomy and expertise. Additionally, because clinicians may be wary that outcome assessment might become just another metric that will be used to evaluate their performance, outcome assessment needs to be framed as organizational growth or quality improvement opportunities rather than punitive metrics. Simultaneously, to identify areas for improvement, members of this breakout group suggested that clinician accountability for process measures such as data capture rates are necessary to ensure representative data to monitor practice patterns and clinical outcomes.

Even if a learning community perceives value in using data and are engaged in the process, barriers may exist in accessing, interpreting, and communicating such data, especially at the point of care. However, such access is essential for using data to inform care. Access by frontline clinicians needs to be intuitive and embedded in routine workflows so that the data can be most useful to the clinician and the patient. Scores also need to be interpretable by those who may not be experts in outcome measurement and may not be familiar with the specific measure or data. For example, providing a concrete point of reference, such as how a typical adult would perform or a cut-off value indicative of fall risk, can help clinicians and patients understand the data. Visual displays may also help with interpretability of data that is fed back at the point of care.[59] Developing and sharing of scripts related to using data for shared decision-making was also noted as an opportunity to facilitate point of care use by frontline clinicians.

Lastly, group members cautioned about the possibility of exacerbating disparities through using patient-centered outcomes. They noted that low-income and other patients who may benefit the most from data-informed care are more likely to be seen in under-resourced facilities without capabilities to develop complex LHS practices because of limited information technology infrastructure or local expertise in outcome measurement. To address facility-level inequities, group members suggested that the rehabilitation LHS community create generalizable learning toolkits and solutions like dashboards that can be implemented without the need for every organization to initiate a full custom build of the EHR. Additionally, patients' social determinants of health must be considered when using patient-centered outcomes data.[58] For example, when comparing outcomes between practices or clinicians, it is important to adjust for social determinants of health, clinical characteristics, and other factors. Without such adjustment, it may appear that those who treat more complex patients have worse outcomes. Group members also noted that continuous evaluation is necessary to ensure that there are no unintended consequences of using patient-centered decision support tools. However, they acknowledged challenges with comprehensively evaluating the equity of such tools, given limitations of available data. For example, more distal endpoints such as hospital readmissions and longer-term functional outcomes may be needed to evaluate the use of a patient-centered tool in acute care that guides discharge destination decisions.

Conclusions

The 2024 *Power of Patient-Centered Outcomes in Rehabilitation Learning Health Systems Summit* provided a forum for knowledge exchange and open discourse across the lifecycle of patient-centered outcomes in rehabilitation. Through the panel presentations and associated breakout discussions, specific challenges in the selection, capture and access, analysis, and use of these measures were explored, with a focus on opportunities to systematically advance the field. Importantly, across each of the lifecycle domains, there was discussion involving collaboration within a learning community and understanding their respective priorities, improving processes for data standardization, and placing equity considerations at the forefront at each step of the process. Systematic change to overcome the identified barriers will require long-term investment among members of learning communities within

and across health care systems, both specific to rehabilitation and more broadly. Partnerships with policymakers, insurers, and regulators are also needed to ensure that patient-centered quality measures support rehabilitation priorities and that incentives are aligned to support widespread implementation of patient-centered outcomes. Given the preliminary state of the field, much work remains to achieve the long-term goals and even develop a related strategic framework, which will require collaboration with other stakeholder entities with the aim of arriving at a formal consensus with respect to actionable next steps. It was our aim through both the Summit and this summary report to serve as a catalyst for future efforts within rehabilitation LHS. Ongoing activities with an expanding learning community stemming from this Summit are focused on more concrete and specific deliverables to accelerate the provision of person-centered, data-informed, and value-based rehabilitation care.

Keywords

Learning health systems; Patient-centered outcomes; Rehabilitation

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