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Clinical Registry Governance:
Vetting the Value of Participation

Health system growth is driven increasingly by public rankings and centers of excellence designations. While the calculus behind these ratings can vary significantly, one near constant is the use of clinical registry participation and data to assess hospital performance. At the same time, there has been a proliferation of registry options – growing to more than 153 national clinical registries in United States by 2017[i]. Today, hospitals participate in an average of 10 registries and the top 20 registries are expected to grow in participation at an average of 7% each year until 2021[ii].

In addition to their role as the cornerstone of a providers' advanced quality measurement program, registries are increasingly recognized by government, accreditors, and private payers within key quality and value-based payment programs. For example, by 2018, nearly 70 percent of the more than 50 specialty society registries were used by the Centers for Medicare & Medicaid Services to measure the quality of clinical care. Payer programs like the Blue Cross Blue Shield Blue Distinction Centers and Aetna Institutes of Excellence/Quality use registries to evaluate facilities for these quality distinctions. Further, the Joint Commission recognizes registry participation for fulfillment of certain requirements in several of its hospital and disease-specific certifications.

However, it is nearly impossible to engage with all registries, so health systems must determine the right number and mix of registries for them and ensure they capture full value for their participation. For even the most seasoned quality improvement leaders, vetting the value can be a daunting task. This whitepaper offers guidance to evaluate new or existing participation and measure clinical registry value and success.

Value must be defined by identifying clear goals for participation such as measurable quality improvement, increased physician engagement, and greater patient volumes. In most cases, achieving the stated goal requires more than simply submitting data. Success likely requires dedicated performance improvement effort, provider engagement, and a true champion. These factors can be summed into three key areas: People, Investment and Data Infrastructure. These factors must be incorporated into the decision-making process to help calculate the full investment as well as highlight potential roadblocks.
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People

Clinical registries are designed as evidence-based collection warehouses that drive performance improvement and enhance patient outcomes.[iii]   As such, a primary goal for success is the development of a system that enables the information to become actionable data that drives performance. These systems require executive oversight. To achieve this, it is vital to understand what drives your executive audiences and select the right physician champion.

Design your business plan to appeal to key stakeholders.

CEO: Focus on the benefits of publicly reported outcomes for public relations and marketing opportunities.

CFO: Enhance revenue potentials of increasing patient volumes and cost reductions relative to performance improvement.

Ask yourself these questions:

- *What are the priorities of the organization's board?*
- *What is the registry's mission?*
- *Based on the registry's mission, which executive or senior leader may have interest in the registry participation or data?*
- *Who might serve as your physician champion?*

The value achieved from registry participation is a direct correlation to its leadership. Key to the registry leadership is an executive sponsor and a physician champion. The champion should illustrate values like perpetual learning, transparent collaboration, and constant process improvement. He or she should also be an expert in change management.

Accordingly, the registry leadership will be able to make administrative and clinical practice changes to improve processes, scores, and outcomes according to the registry data.

Staff

Almost as important as leadership, registry staff will impact the value received as a result of participation. Registry participation requires a skilled workforce that clearly understands the registry guidelines, data elements, and how to translate the information into performance improvement initiatives.

Often within the provider environment, registry staff are tasked with managing registry participation in addition to their other duties. The ideal support model would include an exclusively dedicated staff to avoid role corruption. However, due to resource constraints, it is not uncommon to have teams managing registry participation as a means to break up responsibilities across multiple positions. An increasingly popular alternative to the registry team is engaging external support services. The external support system safeguards the focus, typically offers access to unique skillsets, and introduces an unbiased data abstraction process for added accuracy.

Regardless of the model, staff must be equipped to abstract accurate data to realize the value of registry participation. The impact that inaccurate data can have on an organization's reputation and physician trust are too great to take for granted. For example, many providers assume the data is accurate based on trust built through previous positive working relationships. However, prior success is not a guarantee if that individual is not involved in ongoing training and is not receiving the resources and support needed to adapt to new requirements. It is imperative to develop a quality assurance program that eliminates the potential of inaccurate data. While there are several ways of validating clinical accuracy, an inter-rater reliability (IRR) assessment is considered a best practice.

To ensure the registry staff will increase the value of registry participation, pose these questions:

- *What training and resources will they need?*
- *What external support might be available to help offset the burden?*
- *What conferences and continuing education will be necessary to ensure everyone is staying up to date on best practices?*
- *What is the risk of turnover and how will this be addressed when it occurs?*

Skill	Abstractor	PI Specialist
Knowledge of the Target Population	X	X
Technical Aptitude	X	X
Detail Orientation	X	X
Communication		X
Leadership		X
Influence		X

Investment

Due to the disparate registry governing systems employed by most health care providers, it can be difficult to point to an overall registry investment. While the average facility participates in between 5 to 10 registries, few leaders can identify them. Nevertheless, identifying existing participation is the first step in understanding the overall registry investment.

Participation fees, associated technology, training, and resources comprise your total investment. The cost of participating in the registry is typically a small sum paid annually to the professional society. Most registry participation requires additional technology that captures data from the Electronic Medical Record (EMR) and submits the data to a third-party warehouse. A small number of registries offer complimentary technology, such as the National Cardiovascular Data Registry's online tool, to collect and submit the data. The size of technology investment typically correlates to usability of and analytics within the platform. As registry participation is a means to obtain meaningful clinical data, greater analytics to understand the data-formed insights is ideal. Further, the greatest challenge and largest investment to participate in a registry is internal resources to abstract. In fact, 80 to 85% of the clinical registry abstraction is manually performed by hospital staff.[iv] As a result of the resource challenge, usability of the technology becomes acutely more important.

Hospitals and health systems have few sources to obtain a clear understanding of the resource commitment needed to keep up a facility's specific registry needs. The following table is a snapshot of the full-time equivalent (FTE) requirements for completing data abstraction for the 14 most-commonly reported registry case types. The data is based on abstraction times from a sample of more than 600 facilities across the country. The data indicates that nearly 4.5 full-time staff members are required to keep up with the case load presented. At the very least, a hospital participating in five registries — the U.S. average — would need at least 1.5 full-time staff members to keep up with its registry case load.

Registry	Case Type	Average # of Cases per Month	Hours per Month - Abstraction Only	Efficiency, IRR, and PTO Offsets	Total Hours per Month	FTE Requirement (Based on a 40-hour week and 4.2 week month)
ACC - Afib	AFib Ablation	12.21	24.86	9.94	34.80	0.20
ACC - Chest Pain MI	Chest Pain MI - Basic - Low Risk	21.55	21.22	8.49	29.71	0.17
ACC - Chest Pain MI	Chest Pain MI - Basic - Unstable Angina	4.82	7.72	3.09	10.80	0.06
ACC - Chest Pain MI	Chest Pain MI - Basic Data Set	16.84	30.32	12.13	42.45	0.24
ACC - Chest Pain MI	Chest Pain MI - Full - Low Risk	14.82	19.27	7.71	26.98	0.16
ACC - Chest Pain MI	Chest Pain MI - Full - Unstable Angina	4.97	7.08	2.83	9.91	0.06
ACC - Chest Pain MI	Chest Pain MI - Full Data Set	25.58	62.68	25.07	87.75	0.51
ACC - ICD	ICD	8.65	16.08	6.43	22.51	0.13
ACC - PCI	Cath Diagnostic 5.0	45.20	65.76	26.30	92.07	0.53
ACC - PCI	Cath PCI 5.0	38.26	83.02	33.21	116.23	0.67
GWTG Stroke	GWTG Stroke - Comprehensive	26.69	67.39	26.96	94.35	0.54
GWTG Stroke	GWTG Stroke - Standard	13.92	26.86	10.74	37.61	0.22
GWTG-CAD	GWTG-CAD	20.00	42.00	16.80	58.80	0.34
STS-ACS	STS-ACS	18.00	80.10	32.04	112.14	0.65
TOTAL FTE REQUIREMENT						**~4.5**

Source: An analysis of Q-Centrix's archive of registry abstraction information.

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The table above includes an allotment of time for an inter-rater reliability review program (IRR) to validate the accuracy of the data abstracted. The requirement of a validation system, such as an IRR, to ensure continued accuracy is essential as the complexity of registry data continues to increase. When quality data is inaccurate, it breeds mistrust among clinicians; and ultimately, impedes process improvement. Therefore, a data validation program must be embedded into any registry program abstraction workflow. Accordingly, the time spent by or number of resources required will increase.

Finally, most registries require certification and ongoing education. Certification programs can be in-person or virtual and range from hundreds to thousands of dollars, depending upon the complexity of

the registry data. Further, national or local conferences offer training associated with any specification updates. Beyond registry-specific training, consider ongoing skills training as an additional investment depending upon the needs of the team and the overall talent strategy.

Developing a return on investment (ROI) for participation in an existing or potential registry should correlate to the most valuable outcome being in performance improvement and better patient care. As such, it will be important to offer benchmark data that illustrates how like organizations benefited from participation. Most registries promote the benefits prominently within their own marketing. Potential metrics to consider are decreased length of stays; fixed costs in patient care management; increased efficiency; and in some instances, higher reimbursements from payors. Additionally, ROI can include the result of marketing efforts for the system or facility based on participation. Sites like hospitalcompare.com; publicly shared ratings; or centers of excellence designations are promotional hallmarks that impact patient health care decisions. In fact, in a 2019 consumer survey more than 60% of health care consumers indicated that they were more likely to select a hospital recognized as a center for excellence for treatment of serious medical conditions.[vi] These badges of honor obtained from registry participation can be hung throughout digital real estate like social media and corporate websites to win patient market share.

Data Infrastructure

Now that you have established the right people and investment for your program, the next step is determining the data infrastructure. Fragmentation of health care data is common. In fact, many vendors specifically design their products to prevent data flow across systems. Ideally, the unstructured data from the medical record is abstracted into an external registry platform where it is structured into defined elements (curated), and then both submitted to the society and transferred back into the organization's data infrastructure. This process is called round tripping. Unfortunately, all registry technology vendors do not have functionality to deliver this final step. If they do offer this service, the fees can be exorbitant. Even worse, you may be charged to move data from one version or instance to another within the technology platform.

Key Points for Budget Planning
☑ Who are the decision makers and what information is most important for them to approve the request?
☑ Do you have the correct team in place for registry success?
☑ What are the real costs? • Registry participation • FTE's to abstract and disseminate data • IRR/Data validation costs • Training, education, and certification of staff • Data Infrastructure and management

To accomplish this end, there are key questions to ask registry technology vendors:

- *How will the vendor ensure access to the data within the platform?*
- *How will the vendor support the export of the data for other platforms?*
- *Is there a specific fee structure that applies for the ETL process (Extract, Transform, Load)?*
- *At what frequency will the ETL process occur?*

Registry data is growing in complexity and meaning. Therefore, it is important that internal analytic support teams are properly trained to pull the data accurately for reporting purposes. Data analytics teams often lack the clinical understanding necessary to build meaningful reports. Consequently, they may require leadership or guidance in their reporting efforts from a member of the registry team.

Realizing the Value

As payors and insurers continue to look for means of stratifying payments through Value Based Purchasing, registries are prime resources to assist in aligning incentives to ensure that the right care occurs at the right time, every time. Many registries are already incorporated into national ranking methodologies (e.g. US News and World Report), or in insurers' narrow network tiers through defining centers of excellence (e.g. BCBS Michigan). Hospitals are also operating amid an empowered patient movement. Growing demands for price transparency and enhanced insurance options, like expanded provider networks and the availability of health savings accounts, illustrate consumerism in health care is unabating. Therefore, it is more important than ever that providers understand patients' preferences when choosing where to go for treatment.

A Q-Centrix-commissioned survey of more than 1,200 consumers in December 2019 found recognition for high-quality care was overwhelmingly important when choosing a provider. For example, when asked to rank factors that influence their choice of hospital for treatment of a serious medical condition, more than half of respondents (53%) selected recognition for high-quality care as their most important factor over physician referral (24%), insurance referral (12%), and personal recommendation (11%). Additionally, the majority of respondents felt it was highly important for hospitals to communicate to their patients that they are a center for excellence.

There are many opportunities to realize the value of participation in registries outside the clinical insights. In fact, the competitive advantages have become almost equally as important. There are resources and partnerships available to help maximize value, and Q-Centrix is one of them. Q-Centrix® aims to measurably improve the quality and safety of patient care in the U.S. through the use of its market-leading technology platform, Q-Apps®, that augments the clinical intelligence and efficiency of the industry's largest and broadest team of nurse-educated, Quality Information Specialists. Processing in excess of two million quality data transactions annually, Q-Centrix is a comprehensive quality partner to hundreds of hospitals, providing quality data solutions, including quality data capture, surveillance, measure calculations, analysis, reporting, and improvement solutions. Q-Centrix's growth equity partner is TPG Growth, a premier, global private equity growth firm. For more information about Q-Centrix, visit www.q-centrix.com.

i   Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review, Dewan Md Emdadul Hoque

ii   2018 Q-Centrix Registry Market Report, http://images.quality.q-centrix.com/Web/QCentrix/%7B1e198707-fe97-4859-9563-9cc368fdf90d%7D_Healthcare_Quality_Industry_Report.pdf

iii   Registries for Evaluating Patient Outcomes: A User's Guide. 3rd edition.

iv   2018 Q-Centrix Registry Market Report

v   2019 Q-Centrix Annual Report

vi   2019 Q-Centrix Annual Report/Consumer Survey