MEASURING REGISTRY KEY PERFORMANCE INDICATORS

In order to measure key indicators of progress toward an intended outcome, many groups measure the key performance indicators (KPIs). KPIs allow an organization or group to focus on strategic and operational improvement and assist with decision making through analysis of data to focus on areas that are of high importance.

STEP 1: CREATE GOALS AND OBJECTIVES

It is essential that the purpose of the registry is determined. For example:

- Number of visits to the registry site
- Build a contact registry of the patient community
- Engage direct participation in the registry
- Grow your number of third-party partnerships

STEP 2: IMPLEMENT CRITICAL SUCCESS FACTORS (CSF) FROM THE GOALS & OBJECTIVES

Critical Success Factors (CSFs) are key activities that your organization should focus on. CSFs are special conditions that assist with meeting research goals and objectives within a specific time frame.

Tips on how you define your CSFs:

- Clearly state what is important
- Prioritize the items of importance
- The CSF should contain an action verb to describe the activity of importance (e.g., expand, manage, recruit, perform, etc.).

An example of a concrete CSF might be the following: Increase registry participation by 100 patients over the next 12 months.

STEP 3: USE THE CSFs TO DETERMINE YOUR KPIs

CSFs are essential components for a research plan to be successful. However, KPIs are calculated measures that quantify the CSFs and enable the measurement of that strategic performance. KPIs are always calculations of Measures determined in the next step. KPIs can provide information about how the project is performing.

An example of how a good KPI can be used to measure your progress might be: Percentage of registry visitors converting to consented participants compared to last month.

STEP 4: GATHER MEASURES

Measures are raw numbers that need to be related to each other to provide the most useful information. The Measures that are determined in this step will be used to gather Metrics in Step 5.

Examples of Measures:

- Pageviews
- Visitors to a website
- Daily support calls to registry staff

STEP 5: OBTAIN METRICS FROM MEASURES

Metrics are expressed as ratios, averages, rates or percentages and are calculations of Measures. There can be many Metrics as Measures can be presented in numerous ways. Metrics should also be defined by a time frame.

All KPIs are Metrics, but not all Metrics are KPIs. The Metric needs to inform how the registry is performing in order to be classified as a KPI.

Examples of metrics:

- Percentage of registry site visitors converting to study participants as compared to last month
- Ratio of registry support calls to online support as compared to last month (# of emails vs support calls)
- Average pages viewed per registry visit compared to last period
- Percent of new study participants compared to last period

CONCLUSION

Below is a table summarizing the five steps highlighted above. The KPIs illustrate how they align with Metrics from Step 4.

	STEP 1 GOALS	STEP 2 CSF(S)	STEP 3 KPI(S)	STEP 4 MEASURES	STEP 5 METRICS
EXAMPLE A	Number of participants in the registry	Increase registry participation by 100 patients over the next 12 months	Percentage of registry visitors converting to consented participants compared to the previous month	Pageviews Total site visitors Daily support calls received	Average site visits compared to the last period Percentage of visitors converting to participants as compared to the previous month

Table Explained:

Since the KPI for Example A is the percentage of registry visitors converting to study participants compared to last month, that value for the initial month may be 9 percent. If in the next month that number is 13 percent, we know that the registry has had an improvement in conversion. This will raise study recruitment and likely increase study participation per the stated goal.

In conclusion, understanding registry goals and objectives and establishing KPIs to measure them yield concrete documentation that study sponsors are either on the right track, or need to make changes to improve the study's performance.

SOURCES:

unilytics.com

kpi.org/KPI-Basics

NORD®
National Organization
for Rare Disorders