

Philanthropy Advisory Service Assessment Metrics

The Open Source Review Process



Philanthropy Advisory Service

About the Philanthropy Advisory Service (PAS)

- A *FasterCures* program designed to help philanthropists understand the research and development landscape and strategically guide their investment in high-impact research opportunities.
- In its pilot phase, PAS developed a Web site, www.philanthropyadvisoryservice.org, featuring the latest medical research developments and objective analysis of more than 20 key nonprofit disease research organizations in Alzheimer's disease, malaria, multiple sclerosis, and tuberculosis.
- *FasterCures* continues to expand the scope and breadth of PAS to increase its value to the donor community while also cultivating greater accountability, transparency, and efficiency at nonprofits.
- Initially supported by grants from the Pioneer Portfolio of the Robert Wood Johnson Foundation and the Bill & Melinda Gates Foundation.

About PAS Assessment Metrics

- Developed in consultation with a panel of expert advisors from the nonprofit strategy, medical research, and venture capital fields, as well as other thought leaders.
- Framework is designed to start a conversation about performance measurement of nonprofit biomedical research.
- Assessment results are intended to provide guidance to donors about performance relative to an organization's mission, and do not represent investment recommendations.
- *FasterCures* will continue to refine the metrics and assessment process to ensure it remains a valuable, relevant resource both for philanthropists looking to evaluate investment opportunities and for medical research organizations seeking ways enhance their effectiveness.

PAS Seeks Your Input

FasterCures presents the PAS assessment metrics, framework, and approach to thoughtful, smart, creative innovators and thought leaders who are specifically involved in program evaluation, philanthropy, or medical research program development or have a particular interest in building efficient and effective organizations.

We invite you to review, critique, and comment on these metrics. We believe that developing and implementing appropriate measurement protocols are key to an organization's success. We also believe that to optimize value and impact, measurement considerations must be grounded on realistic expectations, tangible results, short- and long-term outcomes, and other factors that influence decision-making and priority-setting within each organization.

That's why we seek your valuable input on the PAS assessment metrics. We look forward to hearing from you.

In the following pages, we provide details about the metrics and the process used to evaluate organizations against them, please keep in mind the following questions:

- **Are we measuring the right things?** Do the PAS metrics and assessment criteria measure the right organizational practices and scientific performance of nonprofit disease research funders and institutions? If not, how would you change the existing metrics or their assessment criteria?
- **What else should we measure and how?** Are there additional aspects of organizational practice or performance that you would measure? If so, what criteria would you use to measure them?
- **Are these metrics universal?** Are the same metrics applicable across all types of organizations (e.g., medical research foundations, product development partnerships, research institutions) and diseases?
- **Can we organize or present these metrics better?** Should the presentation of assessments focus on the larger categories—accountability, collaboration, research effectiveness, and resource building—with the current metrics serving as indicators rather than final evaluation pieces?
- **What strategy works best – one-size-fits-all or customized?** Should the assessment of PAS metrics be standardized across organizations, or should assessments be made within the specific organizational context?

FasterCures Metrics Summary

- The *FasterCures* metrics measure an organization's operational process as well as its contribution to the field of disease research. Metrics are aggregated into four major categories – accountability, collaboration, research effectiveness, and resource building – and details for each are provided in subsequent slides.

Operational Process	Accountability <ul style="list-style-type: none">• Planning & monitoring• Milestones• Advisory Boards• Intellectual Property• Access & Delivery	Collaboration <ul style="list-style-type: none">• Industry Partnerships• Knowledge-Sharing• Team Science• Global Research
	Research Effectiveness <ul style="list-style-type: none">• Scientific Advancement• Knowledge Production• Portfolio Congruence• Pipeline Profile	Resource Building <ul style="list-style-type: none">• Tools / Resources Dev.• Research Training• Patient Organization• Clinical Trials Networks
Field Contribution		

Accountability: The degree to which an organization engages in planning, demonstrates transparency, and upholds responsibility to stakeholders.

Review Considerations:

- Are we measuring the right things?
- What else should we measure and how?
- Are these metrics universal?
- Can we organize or present these metrics better?
- What strategy works best – one-size-fits-all or customized?

Metric	Definition	Measure	Importance
Accountability: The degree to which an organization engages in planning, demonstrates transparency, and upholds responsibility to stakeholders.			
Planning & Monitoring	Establishes a research strategic plan for managing a portfolio of research projects and evaluates itself against the goals and objectives outlined in the plan	<ul style="list-style-type: none"> • Existence of a strategic plan that responds to the needs of the field and incorporates measurable goals • Evidence of monitoring efforts at regular intervals using a performance management system 	Organizations taking a proactive approach to understanding their position in the disease landscape, to developing a research strategic plan, and to monitoring research portfolios are better able to target the research “investments” where they will have the most impact towards understanding and curing disease. Those that incorporate a feedback loop from the patients and key constituencies ensures the plan is relevant to its stakeholders and responds to the needs of the field.
Milestones	Utilizes milestones to measure and manage scientific advancement against its research plan and project goals	<ul style="list-style-type: none"> • Alignment of project milestones to overall research plan • Demonstrated use of milestones to secure future funding • Evidence of terminating underperforming projects 	Organizations that require achievement of milestones for funding, as appropriate for the duration of the grant, ensure that focus is maintained on key activities and vital resources are appropriately distributed to efforts and researchers demonstrating progress.
Advisory Boards	Has established active advisory boards, with appropriate composition, that provide external, objective guidance at regular intervals	Effective use of advisory boards that have balanced membership, adequate turnover, and whose decisions are key inputs to leadership and Board decisions	Organizations can convene scientific, clinical, business, and other advisory boards to validate research excellence as well as provide guidance in developing and executing their organizational strategy. These boards should have the relevant skill and experience mix for the organization’s mission and membership should turnover to ensure the benefit of new perspectives.
Intellectual Property (IP)	Has established an actionable IP policy aligned with the organizational mission	<ul style="list-style-type: none"> • Existence of IP policy consistent with mission • Demonstration that efforts to commercialize appropriate technologies are pursued 	IP is an important consideration when sharing knowledge among researchers as well as when enticing industry for drug development. An IP policy should be documented, enforced, and aligned with the organization’s mission, strategy, and goals.
Access & Delivery Strategy	Provides a strategy for ensuring candidate interventions can be made available to the target population, particularly in endemic countries	Existence of a robust strategy that engages and has been vetted by product constituencies, addresses affordability, and is timed appropriately to the product development timeline	Candidate therapies are not effective if they cannot reach the target patient population. There are several obstacles that impede access to interventions in the developing world including lack of healthcare facilities, skilled professionals to administer care, and political will. Organizations with missions of delivering novel therapies to these regions will need to implement strategies for ensuring the access and delivery obstacles can be overcome in a timely manner.

Collaboration: The degree to which an organization can engage and nurture relationships that accelerate the overall funding and research cycle.

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Metric	Definition	Measure	Importance
Collaboration: The degree to which an organization can engage and nurture relationships that accelerate the overall funding and research cycle.			
Industry Partnerships	Has formed arrangements to engage with industry towards product development or has a mechanism and strategy for moving research towards commercialization	<ul style="list-style-type: none"> • Existence of industry relationships and/ or drug development subsidiaries • Existence of a commercialization plan if no industry partnerships • Demonstration of feedback loop from partners 	Organizations engaging in partnerships, particularly with industry, will help to accelerate the translation of basic science at the lab bench into clinical application in the market. Partnership arrangements may differ and include instances of nonprofit venture funding of for-profit research.
Knowledge-sharing	Employs policies and practices to facilitate sharing of data (both internally and externally) from projects funded by the organization	<ul style="list-style-type: none"> • Existence and execution of policy • Demonstration that the knowledge shared has made a relevant contribution to the field 	Sharing knowledge from studies helps to accelerate the research process by equipping scientists with data to identify studies with potential impact as well as to further inform their own scientific questions. In-person sessions such as annual scientific retreats as well as open access publishing can expedite the knowledge-sharing process and reduce the information dissemination cycle.
Team Science	Funds / conducts goal-oriented, team-based science with a translational endpoint, in addition to single- investigator projects	Existence of multi-investigator projects to target large, complex scientific questions	Organizations funding team science help to facilitate collaboration among leading research stakeholders, to focus innovation that benefits patients, and to shorten the cycle of discovery and development.
Global Research	Funds or collaborates on international research initiatives	Existence of international funding or collaborations	In an ever-increasing global environment, it is important for organizations to acknowledge a geographic position within a global research environment and build international relationships among top researchers, industry partners, funders, etc. around the world, as appropriate.

Research Effectiveness: The degree to which the organization's research portfolio yields sufficient data and deliverable returns to achieve its stated mission.

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Research Effectiveness: The degree to which the organization's research portfolio yields sufficient data and deliverable returns to achieve its stated mission.			
Scientific Advancement	Results in generation of scientific deliverables (e.g., assays, targets, pathways, biomarkers, etc.)	<ul style="list-style-type: none"> • # of scientific deliverables as % of those planned • Rate of projects moving through the R&D pipeline as compared to the planned rate 	Research projects that produce deliverables and advance candidates through the R&D pipeline per their project plans demonstrate the ability of the organization to identify capable investigators and to bring together the necessary resources to achieve the desired outcomes.
Portfolio Congruence	Achieves a research portfolio that is distributed appropriately and aligned with the organization's mission and stated goals, and that contributes significantly to the needs of the field	<ul style="list-style-type: none"> • Distribution of research funding across types and stages as compared to organizational objectives and field needs • Share of overall pipeline and/or contribution to the diversity of the overall pipeline 	Organizations that demonstrate research portfolios that are congruent with their goals and objectives are appropriately stewarding their research funding in efforts to achieve desired outcomes. This validates their planning and resource management efforts to focus on outcomes. For organizations with missions to deliver novel products to the market, their portfolio must add value to the overall pipeline of products for the disease and purpose.
Knowledge Production	Results in annual generation of new data and knowledge for the field	Annual measurement of: <ul style="list-style-type: none"> • # of presentations • # of publications • # of citations 	Research that is presented, published in peer-reviewed publications, and then subsequently cited, especially by those in varying disciplines, demonstrates the ability of the organization to identify high-quality, high-impact research and thus to efficiently allocate funding to these research efforts. Knowledge that drives the advancement of ideas through drug development is particularly valuable to the field.

Resource Building: The degree to which the organization contributes critical resources and infrastructure to scientific advancement.

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Metric	Definition	Measure	Importance
Resource Building: The degree to which the organization contributes critical resources and infrastructure to scientific advancement.			
Tools/ Resources Development	Funds the creation, maintenance, and expansion of infrastructure and resources to meet the needs of the field	<ul style="list-style-type: none"> • % of total grant funding dedicated to tools / resources • Congruency of tool development with their plan • Contribution of tool to the field 	More resources must be readily available to the research community, including predictive animal models, interoperable clinical and research databases and systems, comprehensive biobanks, information technology platforms, and data standards and protocols. Effective research resources are essential to expand available datasets and analytical capabilities that are necessary to accelerate and drive research from discovery to the clinic.
Research Training	Funds training programs to develop a new cadre of translational researchers to meet training needs in the field	<ul style="list-style-type: none"> • % of total funding dedicated to translational research training • Congruency of training with their plan • Contribution of training to the field 	Training is required to develop a cadre of researchers who have the multidisciplinary skills necessary for a R&D environment focused on translational and clinical research.
Patient Organization	Dedicates resources to understanding and organizing their target patient population	<ul style="list-style-type: none"> • # of patients organized in a patient registry as proportion of disease burden • Understanding of the patient profile as evidenced by the segmentation of patient population (by geography, subtype, ethnicity, etc) 	Understanding and engaging patient populations is essential to developing effective treatments. Patient enrollment to clinical trials is one of the most significant hurdles for conducting clinical research for new therapies. Therefore, efforts like registries that organize patients and potential research participants enable expedited study enrollment and overall acceleration of the research process. These registries also provide data to better understand the patient population and thus design effective intervention trials.
Clinical Trials Networks	Organizes a group of sites that are trained in administering clinical trials for a particular disease	# of sites organized in a clinical trials network	Clinical trials networks create a group of research sites that are connected through common informatics systems to share data, employ consistently trained clinical trials coordinators and staff, are attractive for industry partnerships, and thus are able to more quickly advance the clinical development of promising compounds. Clinical trial network development that incorporates business and project management training is particularly valuable.

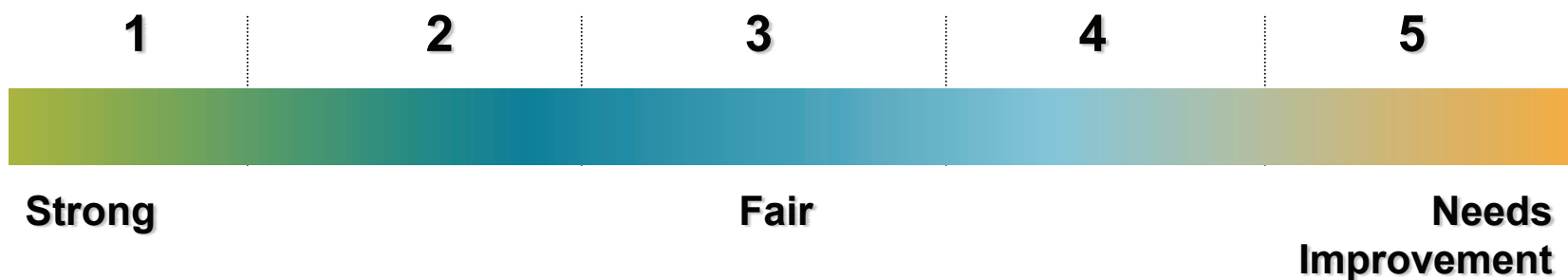
PAS Assessment Process Summary

FasterCures utilized an assessment process that is systematic, well-informed, and objective. Each PAS organization was assessed within the context of its stated strategy, age and size, as well as the state of research for the disease of interest. Each report was reviewed by a number of third-party advisors, including an Organizational Review Board (ORB) and disease-specific Scientific Advisory Board (SAB). Input from these advisors, as well as from the *FasterCures* team, all contributed to the final assessment. The process is outlined below:

- The **ORB provided a numeric score of 1 – 5 indicating the strength of each organization’s performance** relative to each metric. The ORB convened to discuss and debate the scores for each organization and the average score of the ORB became one component of the final score.
- The **SAB was consulted specifically to address how the organization’s research portfolio and accomplishments have benefited the greater community.** Feedback from the SAB was taken into consideration in formulating *FasterCures’* score, the second component of the final score.
- *FasterCures* then **calculated the average of the two scores.** The Accountability and Collaboration metric scores were combined in a 50:50 (ORB: *FasterCures*) ratio and the Research Effectiveness and Resource Building metrics were combined in a 30:70 (ORB: *FasterCures*) ratio in order to reflect the SAB input incorporated into the *FasterCures* score.
- The numeric system allowed more discrete understanding of the relative differences in scores, which will help to refine the overall method and to identify best practice benchmarks. However, **this is ultimately a qualitative assessment, so the numeric scores were then translated into the final outcomes of Outstanding, Strong, Acceptable, or Needs Improvement** according to a set of scoring ranges. Qualitative scores were only overturned by *FasterCures* if new information was made available after the scoring had taken place.
- Finally, **all organizational scores were compared to one another at a high-level** to ensure that qualitative scores made sense for each organization within the context of the greater research landscape.

Numeric Scoring Definitions

- **1** – The organization’s activities in this area are fully consistent and in alignment with its stated strategy and profile (i.e., size and age). Activities are superior in both goals and outputs/outcomes.
- **2** - The organization’s activities in this area are fully consistent and in alignment with its stated strategy and profile and appear to be well planned and executed.
- **3** – The organization’s activities in this area are not entirely consistent with its stated strategy and profile although they appear to be sufficiently well planned and executed OR the organization’s activities are fully consistent and in alignment with its strategy and profile, however they could be more effectively planned and executed.
- **4** – The organization’s activities in this area are partially or not entirely consistent with its stated strategy and profile. Activities could be more effectively planned and/or executed.
- **5** – The organization’s activities in this area are not consistent with its stated strategy and profile and appear to be poorly planned and executed.



Qualitative Scoring Definitions

The following provides guidance for interpreting the qualitative assessment results:

- Outstanding – The organization’s activities for this metric are fully consistent and in alignment with its stated strategy and organizational profile.* Activities are superior in both goals, outputs/outcomes, and impact. This score is reserved for exemplary performances.
- Strong - The organization’s activities for this metric are fully consistent and in alignment with its stated strategy and organizational profile.* Activities appear to be well planned and/or executed, however, impact may not be yet fully understood.
- Acceptable – The organization’s activities for this metric are not entirely consistent with its stated strategy and organizational profile* although they appear to be sufficiently well planned and executed OR the organization’s activities are fully consistent and in alignment with its strategy and organizational profile, however they could be more effectively planned and/or executed. Acceptable scores may also reflect appropriate preparations for activities that will be key elements of future phases of an organization’s strategy.
- Needs Improvement – The organization’s activities in this area are generally not consistent with its stated strategy and organizational profile.* Activities could be more effectively planned and/or executed.

* For Research Effectiveness and Research Building metrics, alignment with the needs of the field is also considered.

Questions for Consideration

As previously mentioned, we hope you consider the following questions as you review the PAS metrics assessment:

- **Are we measuring the right things?** Do the PAS metrics and assessment criteria measure the right organizational practices and scientific performance of nonprofit disease research funders and institutions? If not, how would you change the existing metrics or their assessment criteria?
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Ways to Respond

Feedback can be submitted in several ways:

- Through the comments section at <http://bit.ly/9piwin>
- By email to philanthropy@fastercures.org