Insight

Health Research Management Practice

Patients and Stakeholder Engagement: The Basics

Many organizations now include—or plan to include—patients, other stakeholders, and/or community members in their research enterprise. The goal is to increase the relevancy and timeliness of medical research for patients. Some organizations that have established a solid infrastructure to support this type of engagement have a long track record of success. Other groups have recently begun the process and are now dramatically changing the way they conduct, disseminate, and fund research. Still others question whether such engagement can be managed effectively in their respective fields.

Before launching a patient/stakeholder/community engagement program, the Health Research Management Practice team for Leidos Health recommends that organizations consider the following questions, as the answers will reflect each organization’s unique mission and vision:

1. **How could such a program help your team achieve its mission?**

   How would the program relate to your mission? How could it further your goals? What are the long-term benefits, and what are the risks? A thorough analysis will allow you to tailor your program to your needs and develop measures of success that truly reflect your goals.

2. **Who are your patients, stakeholders, and/or impacted community members?**

   Your patients, stakeholders, or community members may be very different from that of another organization. They can come from very different walks of life and may include the patient, caregivers, clinicians, providers, purchasers, payers, industry representatives, policymakers, educational institutions, and advocacy groups. You have identified the right group if they offer a wide range of experience and expertise that simply cannot be found elsewhere. An effective engagement program must be carefully calibrated so it may encompass everyone who is truly impacted—but no one else.

3. **At what point in the research enterprise should you include your stakeholders?**

   It can be tempting to “keep it simple” by seeking community/patient input at just one stage of the process. However, such limited approaches can backfire if there is no clear plan for ensuring that the engagement is meaningful to both your organization and to the patient/community participants. On the other hand, more is not always better. A participant’s time is a precious resource that must be used wisely. Achieving this proper balance requires constant reassessment—once a program is in place, patient and stakeholder input will be key to achieving this balance.
4. What kind of training must you provide?

High quality training for patients and stakeholders is an essential ingredient for success, and this must be tailored for each activity they will be asked to perform. A well-crafted recruitment survey is critical to determining the experience and expertise of your community. Real-time evaluation of training is particularly useful for new programs, as training and support requirements will often change dramatically over time.

5. How do you develop the infrastructure to support such a program?

Investing in organizational structure and support will dramatically increase the chances of success. It is particularly important to plan for your success; with a new program, the workload often increases exponentially, taking organizations by surprise. An effective project manager is critical to shepherding all moving parts. All personnel need thorough training to understand the goals (and appreciate the value) of the program. An outreach plan that includes a wide variety of social media tools is essential, and an efficient help desk can quickly identify systemic problems that could otherwise sabotage a beginning program.

6. How will you know if the program is working?

Engagement programs can only succeed when success has been clearly defined, and when organizations continually revisit, reassess, and revise the program to ensure it remains aligned with the programmatic goals. The relationship between your organization and your stakeholders is never static, and initial successes will create opportunities for new levels of success. In this way, success can be continually achieved and expanded.

At Leidos Health, we have been supporting patient, stakeholder, and community/consumer engagement programs for over 20 years. Our team of experts has supported engagement at every level and every stage of the research process, including the development of charters; strategic planning; recruitment and training; and sustainment, expansion, and evaluation of programs. Within each organization, programs take different forms such as Ambassadors, Mentoring, Peer Reviewers, Volunteers, Delegates, and Young Leaderships. However, all groups share one common goal: Accelerate the organization’s mission by incorporating expertise that has been previously excluded from the research enterprise. The ultimate goal we share is to generate and disseminate useful, timely, and dependable medical information to our families, our friends, and our communities.

About the authors

**Martin A. Dueñas, MPA,** is the Director of the Health Research Management Practice for Leidos Health | Life Sciences. E-mail: martin.a.duenas@leidos.com

**Isabelle Bisceglio, PhD,** is a Senior Manager for Program Development and Portfolio Management, Leidos Health | Life Sciences.

**Sara Collina, Esq,** is a Senior Expert and Consultant for Leidos Health | Life Sciences.

To learn more about our expertise
Please contact Martin or visit [http://www.leidos.com/health/life-sciences](http://www.leidos.com/health/life-sciences)

About insights, case studies, capability statements, and publications

The Health Research Management Practice team develops Leidos Health papers and publications to support the performance of our clients’ day-to-day operations as part of our core mission to accelerate the prevention, treatment, and cure of disease affecting our friends, our families, and our communities.