

AAMC Initiative on Assessing and Communicating the Value of Medical Research

Stakeholder Engagement Report

About the initiative and RAND Europe's work

In July 2013, the Association of American Medical Colleges (AAMC) launched an initiative to enhance the capacity of the medical research community to respond to increasing public expectations for accountability and transparency in the use of federal research funds. Institutions face growing pressure to assess their investments in research and communicate the impact to their local stakeholders—state governors and legislators, boards of directors, community partners, and patients and their families.

In academic settings, research success has been measured in large part by the traditional academic measures of volume of grant funding and number of peer-reviewed publications and citations. These remain credible and respected markers of quality, though they cannot paint the full picture of the benefits of research. Additional evaluation frameworks can help communicate those successes in ways that resonate with broader audiences.

As part of this initiative, the AAMC has engaged RAND Europe, a not-for-profit policy research organization, to develop an interactive how-to guide that academic medical centers can use to assess the benefits of their research. Their first step was to create a [review](#) of existing approaches to evaluating research.

We then jointly engaged three expert panels of researchers from three domains: health equity research, clinical outcomes-focused research, and basic research to build on RAND's initial review of existing frameworks. At on-site visits, these panel members provided expert input to hone in on which metrics, beyond the traditional academic measures, would be valuable to the diverse stakeholder audiences of U.S. academic medical centers (communities, university research leaders, policy makers, boards of directors, etc.).

To verify and build on the insights of the expert panelists, AAMC, with the support of RAND Europe and the panel members, next performed consultations with representatives from three key stakeholder groups identified by the expert panels for further input:

- Community members
- Research administrators at medical schools and teaching hospitals
- State legislators

This report presents our analysis of consultations with those three key groups. For more details on the initiative, visit www.aamc.org/researchevaluation.

Methodology

RAND Europe created sets of questions for each stakeholder group, exploring perceptions of research conducted within medical schools and teaching hospitals, why this research is important, and how research benefits should be measured and communicated. Questions were tailored to address the interests and perspectives of the different stakeholder groups.

Individuals representing four AAMC-member institutions leveraged existing relationships to gather stakeholder input from community members and state legislators:

- University of California, Davis Medical Center
- University of North Carolina at Chapel Hill
- University of Wisconsin School of Medicine and Public Health
- Wayne State University School of Medicine

In total, two focus groups and four interviews were conducted with community members. Both focus groups had three participants. Two interviews were conducted with state legislators. In addition, AAMC staff interviewed two research administrators. The AAMC secured Institutional Review Board (IRB) exemption for these activities. RAND Europe analyzed the interview notes, identifying elements missing from the how-to guide and from previously collected expert panelist input, existing material that could be strengthened, and key messages about communication with each group.

These inputs were gathered from the three stakeholder groups between April and May 2014.

Community members

Community members were defined for the purposes of this report as individuals or groups of stakeholders who have a stake in the research carried out at medical schools or teaching hospitals. They may be directly involved in the research or belong to a particular community of interest (related to a particular disease or condition, for example).

The 18 community members engaged through this process were a gender, geographic, and ethnically diverse group. Among those participating were heads of community-

based organizations, paid community advisers, and individuals with prior experience participating in community-based research.

The community members confirmed benefits previously identified by the expert panelists, such as improved quality of life and health in the community, health equity, and efforts to translate discoveries.

Community members also identified other ways they determine research success:

- Education of community groups regarding research developments, particularly in relation to prevention.
- Researchers' awareness of specific concerns of community groups, both in terms of the research that is conducted and the way it is communicated.
- Efforts to remedy the lack of trust between the local communities and health research in general (which has been exacerbated by media scare stories) through one-on-one communications and the use of trusted community venues such as churches or community centers.
- Tailoring communications with an understanding of the audience's level of scientific literacy and creating material that they can understand. Suggested communication techniques included written newsletters that could be distributed via email to enhance sharing, verbal presentations at community gatherings, health fairs, use of social media, posters to enhance sharing and inclusivity, logic models, newspaper ads, and radio spots.

The community research stakeholders did not restrict their definitions of successful research to outcomes; there was equal attention to research processes and dissemination of findings. How the research agenda and research outcomes are communicated is equally as important as the actual subject matter.

In summary, community expectations for how research should be assessed and communicated include:

Community member quotes:

"It's not only about compensating participants but how stakeholders are involved in other aspects of research. It's a give-and-take process; there has to be reciprocity. People want to know how this is going to help them; therefore they need to know about outcomes. Researchers need to find ways to keep the community involved after their participation ends."

"For tribal and other community partners, it can be easy to dismiss outcomes if not presented in a way that reflects cultural values and practices. If the topic is well-recognized in the community, people might pay attention, but more often media messages are put out in forms that can scare people away. This speaks to the ability of medical researchers to disseminate outcomes through community venues to ensure they are packaged well, accessible, and ...coming from a trusted source."

- Relevance of the research agenda to community-defined health priorities, with particular emphasis on reducing health inequities and the burdens of chronic disease.
- Engaging community members in all phases of the research process, including dissemination.
- Educating communities about research findings of relevance to health promotion and disease prevention in a culturally appropriate and respectful way.

Research administrators

Research administrators largely confirmed findings from the expert panelists in terms of the metrics and measures of interest to them. Three notes about substance and format merit emphasis:

- Collecting anecdotes and vignettes is worth the effort; they give leaders stories to tell.
- Commercialization of research outputs is increasingly viewed as a desirable outcome.
- University leaders and policymakers alike shared that they would welcome proactive rather than reactive reports, which demonstrate an understanding of their time constraints, apply the principles of good information design, and have a standard, predictable format.

While university administrators are themselves a stakeholder audience for research evaluation, they also wear another hat: they are often the messengers when it comes to demonstrating accountability to donors, legislators, trustees, and even voters. Considering both their interests, and their need for information to pass on to other audiences, will likely result in more effective communication with this group.

Some successful strategies for this audience include:



- Building relationships with research administrators through proactive and ongoing conversations and reporting to help build and maintain credibility for the research enterprise.
- Incorporating strategies and tactics to constantly reeducate these stakeholders about long-term research goals, the various complex inputs into research, and intermediate markers of success.

“Academic medical centers (AMCs) have such diverse audiences, they face pressure to be everything to everyone. To survive going forward, AMCs need to be getting messages to all those groups in ways they can appreciate.”

- Recognizing the inevitable time lag between fundamental discoveries and ultimate outcomes, communicate the value of basic science in terms of its applications.

State legislators

The two state senators who participated represent different constituencies and committee responsibilities. One represents a suburban district in a large city, though does not currently sit on any health care or medical research-related committees; the other represents a rural district and chairs an appropriation subcommittee on community health. The two interviews with state legislators primarily served to confirm that the existing messages and associated indicators within the interactive how-to guide cover the main interests of this group. These interests include advances in scientific knowledge, a positive economic impact, improvements in health care delivery, health outcomes, research efficiency, research capacity, health equity and quality of life in the community, and stimulation of private sector research.

One of the interviewees considered “contributions to the knowledge base,” “research efficiency,” and “a focus on long-term goals rather than short-term wins” as markers of success. The other interviewee instead would look for evidence of “positive economic impact/job creation,” “improved quality of life in the community,” and “health care quality and equity.” Even within a stakeholder group, information needs related to research spending outcomes vary widely.

One broadly applicable recommendation for reporting to policymakers: Don’t wait until a specific piece of legislation is being debated; build advocates through regular communication about the value of research.

Summary

Engaging stakeholders validated many of views put forward by experts in earlier phases of the initiative, building on that work while offering novel insights on ways to improve research assessment and communication from academic medical centers. The interviews further confirmed that no one format or approach will suit the needs of all stakeholder audiences. Each of the three groups (community members, research administrators and state legislators) has different preferences for which aspects of the research enterprise are emphasized and how that information is packaged. These preferences relate to the types of decisions that the information will be used to inform.

The insights gained through this stakeholder engagement activity will be incorporated into the initiative going forward as a series of additional metrics for success institutions may opt to collect and report based on the intended audience.

Next steps

The AAMC and RAND Europe will engage with two AAMC-member institutions to develop a brief “proof of concept” report that juxtaposes important academic metrics of research’s value with a selection of the novel, broader metrics identified by the expert panelists and through the stakeholder engagements described above.

Using the institutions’ own data and guided by what has been learned from national and local experts, these reports will aim to demonstrate how assessing and communicating the value of medical research for and to the broadest set of audiences can complement traditional academic measures and paint a fuller picture of the ways in which research benefits institutions, patients, and communities.