



SMRB Working Group on Approaches to Assess the Value of Biomedical Research Supported by NIH

Gail Cassell, PhD

Working Group Chair

Charge Issued by the NIH Director

NIH requests that the SMRB identify appropriate parameters and approaches for assessing and communicating the value of biomedical research supported by NIH.

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Working Group Roster

NON-FEDERAL

- Gail Cassell, PhD (*Chair*)
- Norman Augustine
- Hon. Daniel Goldin
- Gilbert Omenn, MD, PhD
- Arthur Rubenstein, MBBCh

FEDERAL

- Alan Guttmacher, MD
- Richard Hodes, MD
- Stephen Katz, MD, PhD
- Griffin Rodgers, MD, MACP
- Martha Somerman, DDS, PhD

Summary of Key Points Identified by Working Group

- NIH should capitalize on the ongoing innovations in data collection and analysis by intensifying its efforts to systematically, comprehensively, and strategically assess its value. Results can then be used to demonstrate accountability, enhance management, and increase public awareness.
- Though some of what NIH produces is easy to measure, these markers of progress do not begin to fully capture the wealth of NIH's contributions to the world.

Summary of Key Points Identified by Working Group *(cont.)*

- **There are many compelling reasons for NIH to continually improve its ability to assess value** (e.g., emergence of better data and tools, accountability to the public).
- **However, assessing NIH's value is complicated due to a number of factors** (e.g., difficulty demonstrating attribution).
- **NIH should strengthen its assessment of value by undertaking a coordinated, comprehensive strategy to:**
 - ❖ Identify representative study topics;
 - ❖ Improve its data infrastructure; and,
 - ❖ Determine appropriate methodologies based on purpose, audience, and study topic.

INTRODUCTION

- **NIH is responsible for investing public funds in biomedical research and should use funds effectively**
- **There are increasing opportunities and expectations to improve assessment efforts**
- **Assessment results can improve priority-setting and decision-making processes at NIH, but it is first necessary to ensure assessments are sound**

OVERVIEW

- **Three value “streams” based on NIH mission:**
 - ❖ Fundamental knowledge, health effects, and broader societal impacts
- **Challenges to accurately assessing value:**
 - ❖ Proper attribution is very difficult due to time lag and the complexity of the biomedical research and public health enterprises
- **Purpose of assessing NIH’s value:**
 - ❖ Accountability to the public, management of the NIH portfolio and activities and communication of NIH’s value

Findings and Recommendations

(1) Overarching Finding and Recommendation

Finding:

It is extremely difficult to demonstrate the value of biomedical research as a whole and even harder to ascertain NIH's specific contribution.

Recommendation:

NIH should intensify its efforts to systematically, comprehensively, and strategically assess the value of biomedical research for the purposes of accountability, effective management, and public awareness. This will require a sustained investment in strengthening NIH's data infrastructure and a dedicated funding stream or mechanism to support assessment projects.

Findings and Recommendations

(2) Value of knowledge and its application

Finding:

NIH's value is derived from producing knowledge that can be applied to improve health.

Recommendation:

Assessments of NIH's value should draw clear connections between the generation of basic and clinical knowledge and the impact of this knowledge along differing translational pathways.

Findings and Recommendations

(3) Multiple factors and contributors

Finding:

Many factors need to be considered in order to determine accurately NIH's contribution to a particular outcome.

Recommendation:

Credible, interpretable, and useful assessments of the value of NIH should be clear in attributing outcomes to all contributors and adopt a timeframe that is broad enough to include sufficient time for discovery to be applied.

Findings and Recommendations

(4) Many stakeholders

Finding:

NIH affects and is affected by many participants in the scientific and health ecosystems; therefore, many stakeholders must be considered in any attempt to assess and communicate its value.

Recommendation:

NIH assessments should be done in partnership with its many stakeholders.

Findings and Recommendations

(5a) Assessment coordination

Finding:

Numerous attempts to assess aspects of NIH's value have been undertaken by NIH and by many of its stakeholders, but these efforts have not been comprehensive, systematic, or coordinated.

Recommendation:

NIH should establish a trans-NIH Committee on Assessments that will:

- ❖ Develop a strategy to support or conduct assessments of value, including through grants or contracts with external experts
- ❖ Determine a process for strategically selecting study topics that map to a conceptual framework including different translational pathways

Findings and Recommendations

(5b) Data

Finding:

There is insufficient data collection, storage, and linkage between data sets to conduct thorough assessments of value.

Recommendation:

The recommended trans-NIH Committee on Assessments should:

- ❖ Oversee (in conjunction with NIH's recently established "Big Data" committees) NIH efforts to strengthen data needed for assessing value, including:
 - Identifying and gaining consensus on a core set of indicators to be included in its data infrastructure
 - Creating better data linkages with NIH's partners and hand-off sectors

Findings and Recommendations

(5c) Methodologies

Finding:

A suite of rigorous and feasible methodologies are needed to improve assessments of the value of NIH. Of the many assessments that have been undertaken, no single approach has proven entirely satisfactory.

Recommendation:

The recommended trans-NIH Committee on Assessments should:

- ❖ Identify promising analytical approaches and develop an assessment approach guide that outlines the factors to consider and the mix of methodologies (e.g., retrospective, prospective, qualitative, quantitative) that should be employed in attempting to capture value
- ❖ Seek input from external experts in the development of methods and tools to improve assessments of the value of biomedical research

Findings and Recommendations

(6) Communication

Finding:

Effectively communicating the results of assessments of the value of NIH gives the agency the opportunity to increase public understanding of the scientific research process, NIH's mission, and the ways in which biomedical research affects daily life.

Recommendation:

Every assessment activity that NIH undertakes should begin with identifying the purpose of the study and its audiences. Assessment study designs should include diverse communication strategies to disseminate results in ways that will enhance awareness and understanding of the scientific research process among a variety of audiences.

Next Steps: SMRB Approval

- **SMRB activities**
 - ❖ Receive feedback from SMRB members
 - ❖ Receive feedback via public comment
 - ❖ Vote on final report