



Advancing Data Sharing for Implementation Science in Cancer Control Workshops to facilitate collaboration and exchange

May 31, June 7, and June 13, 2022



To address the need to improve the way we collect and use data for the benefit of practice, policy, health, and health care, the National Cancer Institute's (NCI) Division of Cancer Control and Population Sciences (DCCPS) Implementation Science Team and the NCI Cancer Moonshot-funded Implementation Science Centers in Cancer Control (ISC³) organized a series of three virtual workshops titled, "Advancing Data Sharing for Implementation Science in Cancer Control."

The workshops brought together a multidisciplinary group of scientific experts in implementation science; data sharing; epidemiology; behavioral science; community engagement; and qualitative, quantitative, and mixed-methods research. Together, the attendees heard expert presentations and panel discussions and participated in an interactive breakout session to provide input on a process, scope, implications, and trajectory for data sharing in implementation science. The workshops were structured to encourage dialogue and engagement among attendees regarding the norms, communication, and partnerships that would support and facilitate data sharing, and its benefits to communities and science, as well as a discussion on the resources needed to effect change.

This summary outlines the workshop presentations and panel topics, and highlights key themes and considerations for data-sharing practices in implementation science.

Workshop 1: Charting a Roadmap for Data Sharing in Implementation Science and Cancer Control

The first virtual workshop on May 31, 2022, included presentations, panel discussions, and engagement among attendees.

The objectives of this first workshop were to:

- Provide an overview of current NIH policy on data management and sharing;
- Identify ways that data sharing is unique for implementation science; and
- Discuss specific considerations for data sharing in implementation science through case examples.

The workshop began with two presentations on [the 2023 National Institutes of Health \(NIH\) Policy on Data Management and Sharing](#). The first presentation gave an overview of the new NIH policy, the potential impact of sharing data and publications on advancing science and improving practice in health research, and the NCI Cancer MoonshotSM policy for public access and data sharing. It also covered opportunities to help define best practices for managing and sharing data with the research and practice communities. [Watch this session.](#)

The second presentation offered a discussion of the benefits and opportunities for data sharing in implementation science, including:

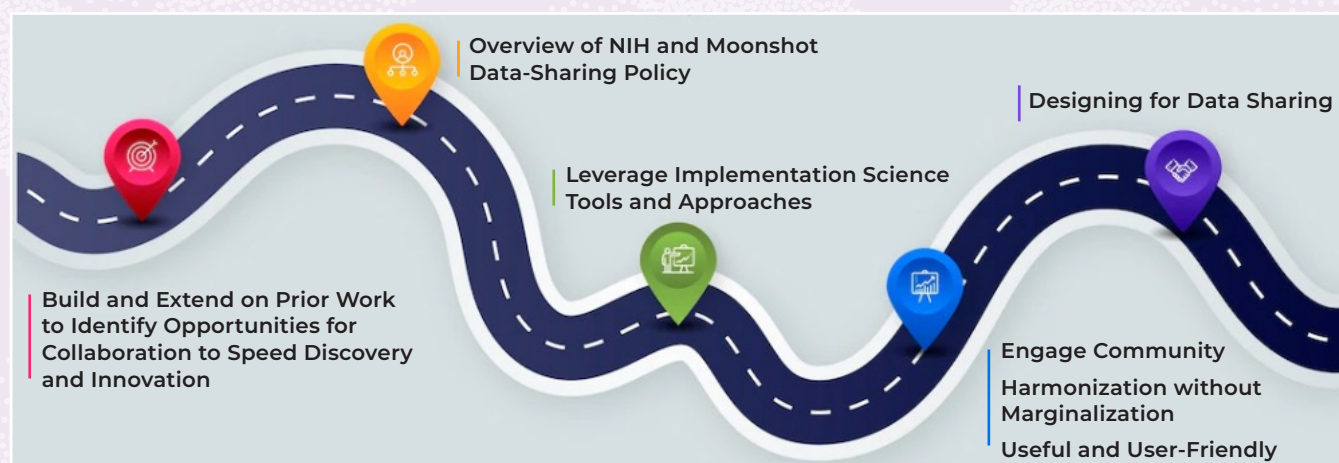
- Bringing together different data sets to produce an evidence base and understanding of context for interventions and implementation strategies.
- Applying implementation science tools and approaches to implement data-sharing policies and norms.

For implementation science, it's important to think about how NIH's data-sharing policy focuses on the end users—thinking about ways to convey information to maximize their access and understanding for engagement, dissemination, and scale-up. Best practices ensure synergy and fair principles in data sharing. [Watch this session.](#)

The next session featured an expert panel discussion on data sharing in implementation science. Panelists discussed why data sharing is vital for implementation science and ways to approach data sharing. There's an opportunity to make data sharing an essential part of our work as researchers—to make it actionable, fun, and innovative. But we need to quickly and easily convey changes in organizational structure, our data-sharing approaches, and our methods of delivering the best care. [Watch this session.](#)

Key Themes from Workshop 1

Overall, the first workshop identified important steps and processes for charting a roadmap for data sharing in implementation science and cancer control.



Workshop 2: Ethical and Social Implications and Considerations for Data Sharing in Implementation Science and Cancer Control

The second workshop was held on June 7, 2022, and featured panel discussions on ethical, privacy, and social implications of data sharing in implementation science. Panelists focused on diverse data types, such as qualitative, quantitative, and mixed-methods data from multi-level data sources, such as individuals, families, patients, providers, health systems, and communities.

The objectives of the second workshop were to:

- Identify different types of data that might be relevant in implementation science; discuss and identify the different forms these data might take; and identify some of the challenges and opportunities for engaging communities in data-sharing efforts.
- Explore ethical, privacy, and confidentiality considerations for sharing implementation science data; identify strategies for collecting and anonymizing data; take a deeper look at how a couple of organizations have created qualitative data repositories; and discuss the value of sharing qualitative and other non-quantitative data.
- Discuss how to share data and with whom; discuss the implications of data-sharing goals and practices within the context of community-engaged participatory research.

The first panel, “Community Voice, Access, and Implications for Data Sharing,” featured panelists with expertise in medical ethics; community-based participatory research; child welfare; and medical sociology, race, and ethnicity, among other subjects. Panelists engaged in an interactive discussion regarding the importance of partnering and listening to clinical and community collaborators throughout the life cycle of research studies in implementation science. [Watch this session.](#)

The second panel, “Ethical and Human Subjects Considerations for Data Sharing,” examined ethical, privacy, and confidentiality considerations for sharing common data elements in implementation science. The panel discussed the many players in data sharing: the data owner, the repository, investigators, and the institutional review board. Where do the research subjects fit in? Once their data is collected and stored, does their involvement end? Can we consider sharing data with researchers, communities, and individual participant subjects? [Watch this session.](#)

Recommendations from Workshop 2

- Start thinking about data stewardship and sharing early in project planning.
- Approach data stewardship through an equity and data justice lens.
 - Data sharing can contribute to data justice and open science by promoting engagement, communication, and access.
- See context as a multilevel concept connected in complicated ways to data interpretation and sharing.
 - What are the micro-, meso-, and macro-level considerations?
- Identify the frameworks, processes, and governance that support data sharing.
- Gain insights on data sharing from repository experts.
 - How do we increase the types of data that can be safely and usefully shared?

Workshop 3: Common Data Elements for Implementation Science and Cancer Control

The third and final virtual workshop on advancing data sharing in implementation science in cancer control was held on June 13, 2022. The focus of this third workshop was on common data elements for advancing the field. The workshop began with a brief summary of the first and second workshop. [Watch this session.](#)

The objectives of the third workshop were to:

- Identify a process for selecting, operationalizing, and prioritizing a set of common implementation data science elements in cancer control; and
- Identify optimal specifications for an ideal platform for sharing common data elements in implementation science, and tools needed to facilitate sharing such elements across studies.

The workshop began with a panel discussion among experts in subjects such as dissemination and implementation science, the mechanisms and measurement of health and disease, and evidence-based practices in health care delivery and other organizational settings. Each panelist described lessons learned and recommendations for common data elements based on their experience in collecting, analyzing, and reporting select common data elements in implementation science in cancer control content areas. Panelists also presented their ideas on the structure, process, and content of an ideal data-sharing platform for common data elements in implementation science. [Watch this session.](#)

Later, attendees were invited to ask the expert panel questions. Some subjects of interest included:

- Requiring data harmonization and sharing from the beginning of a research project;
- Having a coordinating center facilitate data harmonization and sharing; and
- Promoting and developing guidance on the consistent use of implementation science measures. [Watch this session.](#)

Following the Q&A, attendees broke out into groups to first discuss how to create an ideal process for operationalizing and prioritizing common qualitative and quantitative implementation constructs to measure metrics. Then, a second set of groups discussed the specifications for an ideal, common data-sharing platform to facilitate the synthesis and selection of common data elements. [Watch this session.](#)

Key Recommendations from Workshop 3

- Identify a process for selecting, operationalizing, and prioritizing a set of common implementation data science elements relevant to cancer control and harmonization across research projects.
- Discuss and identify specifications for an ideal platform and tools to facilitate sharing and use of common data elements across projects.
- Discuss the benefits of identifying, agreeing upon, and having requirements for common data elements early in a collaborative network and specify the purpose, goals, and rationale.