



The Blueprint: Paradigm Project Updates

At a Glance...

- The Paradigm Project is adapting to the current environment, shifting resources and focus to drive rapid progress toward needed changes in health services research.
- Newsletter format updated to share articles relevant to this new focus. Articles highlighted in September examine equity, community engagement in research, and innovations in data and methods:
 - Approaches to data equity vary: some are calling for elevated data practices, while others are calling for the abolishment of Big Data altogether.
 - Is the open-access model of scientific publishing as revolutionary as advocates have hoped?
 - A first-person account illustrates the imperative and obstacles to combatting racism in the HSR workforce and beyond.
 - Read up on resources about how to meaningfully engage communities in research.



A New Format

"Welcome to the new and updated Paradigm Project newsletter"

Welcome to the new and updated Paradigm Project newsletter.

AcademyHealth suspended publication of this update in February as our community and Nation began to grapple with the full impact of the COVID-19 pandemic and, shortly thereafter, the beginnings of a nationwide reckoning with systemic, pervasive racism and its impact on our communities. On their own, either of these events would highlight an urgent need for transformative change. Together, they demand a response.

The Paradigm Project has an opportunity and mandate to respond to this moment with aggressive action, and we spent the last few months refocusing our efforts and resources to more quickly drive promising ideas toward real world tests.

To do this, we are currently emphasizing the work of four Design Teams that are focused on issues that have been highlighted by the COVID-19 pandemic, as well as issues of racial equity in health services research and health care. This includes projects to:

- Demonstrate, promote and value diversity, equity and inclusion in the health services research workforce;
- Ensure racial equity in big data research.
- Support rapid, open, and useful dissemination of evidence to improve health and health care;
- Help health systems and community-based organizations implement evidence-based interventions to address disparities and increase high-quality, equitable care.

We also combined three Design Teams that were focused on various aspects of community participation in the research process to better leverage their shared interest and expertise.

Going forward, AcademyHealth will use this newsletter to share updates on these projects and on other initiatives that are relevant to the aims of the Paradigm project. As such, you'll find articles and information on ways HSR can:

1. Be grounded in a cohesive vision and shared sense of purpose;
2. Ask the right questions;
3. Involve the right people and partners;
4. Use the right data and methods;
5. Leverage the right incentives; and
6. Deploy the right messengers and messages.

Below are a few recent articles and resources that grapple with or describe these challenges. We hope you find these useful as you work to make a difference in your own communities and institutions.

NOTE: In keeping with the Paradigm Project's work to foster creative thinking by engaging with uncommon and new perspectives, articles may include provocative or non-traditional points of view. Inclusion of these articles doesn't imply endorsement, and all opinions are the authors' own.



On Data...

"To abolish Big Data would mean to put data in the hands of people who need it the most"

In the face of mounting concerns about data equity, researchers and activists alike are rethinking how data can empower community health and minimize disparities. Here are two perspectives on using data to advance equity.

The Urban Institute's project, [Elevate Data for Equity](#), supported by the Robert Wood

Johnson Foundation, is providing knowledge and developing tools for using data to advance equity and community health. A June 2020 [resource](#) outlines how the principles of beneficence, respect for persons, and justice, drawn from the Belmont Report, can be applied to every stage of the data life cycle, along with some useful additional resources that are linked in the article.

Taking a different [approach](#), Yeshimabeit Milner, founder and executive director of [Data for Black Lives](#), proposes abolishing the current system of Big Data altogether. She sees her organization as a “call to action to reject the concentration of Big Data in the hands of a few, to challenge the structures that allow it to be wielded as a weapon of immense political influence... Data is power. Big Data is fascism. To abolish Big Data would mean to put data in the hands of people who need it the most.”



On Innovations in Science Communication...

"Is today's commercialized open-access as revolutionary as advocates have hoped?"

Advocates for an open-access model of scientific publishing hoped that it would lead to the democratization of knowledge. Is today's commercialized open-access as revolutionary as advocates have hoped?

Michael Schulson sees [problems](#) in today's commercialized open-access model, and believes significant questions remain: “As it stands, all trends point to an open-access future. The question now is what kind of open-access model it will be — and what that future may mean for the way new science gets evaluated, published, and shared.” Design Team 5C is grappling with related issues of dissemination. Their focus, however, is on ensuring that research content and outcomes are available, understandable, accurate, and actionable to audiences who might use them.



On Diversity, Equity, and Inclusion in HSR...

"The bar to publish on racial health inequities has become exceedingly low"

Read Namandjé Bumpus' moving [account](#) of her experiences with anti-Blackness in academia, and how the culture of academic science erases the Black experience and centers whiteness. Being “good,” she concludes, is not resisting the recognition of racism; instead, it is looking inward, taking concrete action, and leading by example. Design Team 3A is addressing the lack of inclusion of diverse perspectives in HSR with the idea of a moving experience that leads to a fundamental shift in perspective and sparks actionable change within the field.

The act of recognizing and identifying racism must occur in all aspects of HSR, beyond the workforce itself: in particular, there's an increasing call to raise visibility of racism in research publications. This [blog post](#) contends that "the bar to publish on racial health inequities has become exceedingly low... There is no uniform practice regarding the use of race as a study variable and little to no expectation that authors examine racism as a cause of residual health inequities among racial groups. Absent rigorous standards, the praxis such scholarship offers can be conflicting, potentially dangerous, and ultimately ineffective.” The authors then propose new standards on publishing on racial health inequities for researchers, journals, and reviewers.



On Community Engagement in Research...

"Leaders must avoid the temptation to act in a top-down manner"

This [guidebook](#) proposes an equity-based approach as a way to restore communities as the true authors and owners of research, and to shift the way researchers and funders work with community-based organizations to uncover knowledge together. Chicago Beyond's guidebook not only helps level the playing field, but also addresses unintended bias in research.

An older article compliments the guidebook by offering additional [factors](#) that drive community engagement. It points out that "data-driven and evidence-based practices present new opportunities for public and social sector leaders to increase impact while reducing inefficiency. But in adopting such approaches, leaders must avoid the temptation to act in a top-down manner. Instead, they should design and implement programs in ways that engage community members directly in the work of social change."

Lastly, we'd like to remind all Learning Community members that you are invited to participate in testing conversations with any of the five Design Teams that are currently engaged in this process. If you are interested, please reach out to caitlin.otter@academyhealth.org so that she may match you to a Design Team and schedule a testing conversation with you.

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