

January 31, 2022

PCORI

1828 L Street, NW, Suite 900

Washington, DC 20036

[By online submission at <https://www.pcori.org/about/provide-input/pcoris-research-agenda-proposed-agenda-for-public-comment>]

RE: PCORI's Research Agenda: Proposed Agenda for Public Comment

The Infectious Diseases Society of America (IDSA) appreciates the opportunity to comment on the Patient Centered Outcomes Research Institute's proposed Research Agenda. IDSA represents over 12,000 infectious diseases physicians and scientists devoted to patient care, disease prevention, public health, education, and research in infectious diseases (ID). Our members work across a variety of healthcare settings and in a wide array of ID research.

PCORI has been a leader in supporting comparative effectiveness research and continues to hold a unique role in identifying areas of critical research. IDSA is eager to work with PCORI in aligning infectious disease research priorities with its proposed Research Agenda. Below are examples of critical ID research areas where we believe comparative clinical effectiveness research could significantly improve patient decision-making and health outcomes.

Fund research that fills patient- and stakeholder-prioritized evidence gaps and is representative of diverse patient populations and settings

- In funding clinical trials, support research that prioritizes including diverse participants from a variety of ethnic, racial, gender identity, and age backgrounds to improve representation in clinical research. African American/Black, Latinx and Indigenous populations and adults aged 75 and older [often have incredibly low participation in clinical trials](#), which contributes to health inequities. Additionally, increase inclusion of vulnerable groups like pregnant and immunocompromised patients in clinical research trials when possible.
- Study the effectiveness of recruitment strategies for clinical trial volunteers, and factors that may prevent these strategies from reaching underrepresented populations.
- Support clinical trial research that actively fosters community engagement in underrepresented populations in clinical research trials. Further support should be directed to studies evaluating the impact of community-based and non-traditional clinical trial sites compared to traditional urban academic health centers on community and participant engagement.
- Evaluate the impact of engaging community clinicians and frontline physicians in clinical trial research and development, particularly clinicians and researchers who are a part of the community being studied or who have lived experience of the health issue. Frontline physicians and other community clinicians can offer insight to trial planning. As active members and trusted figures in trial site communities, these individuals help build transparency and public trust. Additionally, they help expand potential trial participant

pools, which can improve trial diversity. Further, [studies](#) have shown that involving clinical researchers can ease the translation of research results into clinical care.

- Include international sites where feasible in funded research trials to increase generalizability of findings globally.
- Proactively fund and develop infrastructure that supports research on emerging infectious disease threats.

Fund research that aims to achieve health equity and eliminate health and healthcare disparities

- Study patient access and barriers to treatment by specialists, including infectious disease physicians, and means to address such barriers such as telehealth consultation. [Studies](#) show intervention from ID physicians during a hospital stay were associated with lower mortality rate, shorter length of stay, and were less likely to be readmitted after discharge. However, many areas lack access to ID physicians, especially rural, at-risk communities. Lack of access to specialty care contributes to adverse healthcare outcomes, and factors contributing to these barriers should be explored and identified through research.
- Research treatment discrepancies in healthcare between demographic groups. For example, [recent studies](#) show racial and ethnic disparities in the receipt of COVID-19 treatment medications, with PCORnet data indicating much lower utilization of monoclonal antibody treatment in COVID-19 patients who were Black, Asian, and Hispanic (relative to white and non-Hispanic patients). Studying factors that lead to discrepancies in treatment is essential to achieving equity in healthcare.
- Identify, study, and mitigate contributing factors to higher rates of ID and ID complications in African American/Black, Latinx and Indigenous patient populations.

Fund research that builds the evidence base for emerging interventions by leveraging the full range of data resources and partnerships

- Approvals for new antibiotics to treat multidrug resistant infections are often based upon limited data from the studies that were feasible to conduct. This approach is necessary to bring new antibiotics to market, but considerable knowledge gaps can hamper optimal early use of new antibiotics for infections that urgently need new treatments but are difficult to study (such as complex infections caused by multidrug resistant pathogens). Post-approval studies on the performance of novel antibiotics for indications with unmet medical needs would be extremely helpful to optimize care of patients with serious infections.
- Research effective strategies for dissemination of essential, at-home diagnostic tests for infections and the potential benefits of these tests, including reducing unnecessary healthcare visits and improving overall patient experience.

Fund research that examines the diverse burdens and clinical and economic impacts important to patients and other stakeholders

- Assess the impact of different methods to increase patient access to health records, and the effect on patient awareness and overall healthcare experience. Simplified, accessible data in electronic health records can help patients take an active role in healthcare decision making.

Fund research that focuses on health promotion and illness prevention by addressing health drivers that occur where people live, work, learn, and play

- Identify effective workplace practices that promote both physical and mental wellness. These types of studies are particularly needed in healthcare systems that have been overwhelmed by COVID, exacerbating a widespread burnout and mental health crisis in healthcare personnel (HCP). Research that identifies contributing factors at the institutional level can help mitigate the mental health crisis in healthcare and other fields facing similar issues.
- Fund comparative research on the effectiveness of strategies for delivering healthcare to underserved communities and rural areas that have traditionally lacked comprehensive healthcare access. Examples may include access to telemedicine, community health workers and federally qualified health centers.

Fund research that integrates implementation science and that advances approaches for communicating evidence so the public can access, understand, and act on research findings

- Determine the best ways to communicate to vaccine hesitant patients and families, including the most effective messengers and messages for subpopulations within the vaccine hesitant community; studies should also examine the resources, tools, flexibilities, and authorities necessary for public health authorities and health care professionals to implement best communications practices.
- Evaluate the impact of strategies meant to improve the adult vaccination rate for diseases like influenza. Adult vaccination uptake was already low before the pandemic and continues to require attention. Studies should also examine uptake disparities and barriers to vaccination as they relate to age, ethnicity, race, and socio-economic status, and identify effective targeted strategies to increase uptake in these groups.
- Determine the best ways to communicate to patients and families about appropriate antibiotic use; studies should also examine the resources, tools, flexibilities, and authorities necessary for public health authorities and health care professionals to implement best communications practices.
- Research the effectiveness of novel strategies to engage the public and target audiences beyond academia in the dissemination of scientific findings and public health recommendations, including digital and social media strategies, live participatory “short talk” events, and community outreach initiatives. This research should address what strategies work best for specific demographics so scientific information can be conveyed in the most easy-to-understand format for diverse groups. Additionally, fund comparative research on the most effective graphic representations of quantitative data when conveying information to public audiences.

- Study the impact of misinformation on trust in scientific research, specifically focusing on key populations most likely to fall prey to misinformation, the effect of misinformation on willingness to cooperate with scientists and clinicians, and the effect of novel strategies in combating misinformation surrounding scientific research.

IDSAs welcomes continued collaboration on these research priorities, and on PCORI's proposed Research Agenda. If you have questions about these comments or would like to connect, please contact Amanda Jezek, IDSA Senior VP, Public Policy and Government Relations at ajezek@idsociety.org.