

Promoting Trust and Inclusion in COVID-19 Research



PROMOTING TRUST AND INCLUSION IN COVID-19 RESEARCH

Rationale

Historically, racial and ethnic minority populations have been excluded from clinical research studies. This, coupled with past research abuses, have at times prevented cutting edge health discoveries from being shared fairly and equitably across all populations. This contributes to persistent health disparities and may make some people hesitant to participate in research.

It is essential that COVID-19 clinical research include racial and ethnic minority populations to reflect the disproportionate impact of the pandemic.

To promote inclusive participation in COVID-19 research, sponsors and researchers must demonstrate trustworthiness among groups that have been traditionally underrepresented. Increasing trustworthiness may provide tangible bidirectional benefits for researchers and participants. Below are a few promising practices for researchers to highlight when engaging new partners to improve inclusive participation, as well as descriptions of how communities might benefit.

Being inclusive and making the products of research available, accessible, and affordable to volunteers and their loved ones can promote trust and support for research in communities.

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Promising Practices

- **Partner with communities to identify high-priority research areas**, as the perceived benefits and value of research vary across communities.
- **Share information on the purpose of research** in easily understandable, culturally informed ways.
- **Share research results** with communities in a timely fashion and in clear, accessible ways.
- **Remain engaged with communities** after the clinical research; share trial updates—like FDA approval, results from other studies, or adverse events—to strengthen community relationships, and build trust and participation.

- **Co-create with community partners** and distribute accessible, trusted resources and services about COVID-19.
- **Be available to answer questions** in easily understandable, accessible ways.
- **Address community members' specific concerns, questions, and needs**, including accurate information about other health topics and services.

- **Engage community members early in research planning.**
- **Demonstrate that the research is just, ethical, safe, and meaningful** for the community.
- **Be transparent about the research process** and how it protects individuals.
- **Acknowledge past research injustices** if relevant. Avoid using “research subject” terminology.

- **During a study, provide needed resources**—such as information, referrals for medical care, preventive strategies, social needs, and digital access—to volunteers and/or the community.
- **After a clinical study**, make successful treatments available to volunteers who received the placebo.
- **After approval**, facilitate making successful treatments available to volunteers and their community.

- **Include community members as paid members** on the research team whenever possible to draw on their lived experiences.
- **Hire and partner with community members** to develop materials, recruit participants, and collect and interpret data.
- **Nurture and mentor young people** in science and healthcare.
- **Increase access to flexible and timely funding** to increase organizational capacity of community-based organizations.

Potential Value to the Community

Increase Knowledge

- Promote knowledge about preventing, diagnosing, and treating COVID-19.
- Increase understanding of short-term and long-term impacts of COVID-19.
- Better prepare communities for future crises.
- Provide knowledge that may benefit future generations.
- Identify resources and services needed to improve community health.

Improve Access to Trustworthy Information

Research volunteers, their families, and friends can collaborate in creating resources about COVID-19 and other health topics with trusted partners.

Build Trust and Understanding in Research

Research volunteers, their families, and friends can help shape the scientific process while learning about the value of science, and how they are protected and respected as volunteers.

Promote Community Access to Research Products

Clinical trials may enable access to new diagnostic, therapeutic, and preventive resources for volunteers and others.

Build Community Capacity

Collaboration with community members in research helps build community capacity and strengthen the intellectual base, including future scientists.