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A Paradigm Shift Towards More Inclusive and Equitable Approaches to Data Access and Utilization After Community-Based Public Health Research

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ABSTRACT: Health equity remains an elusive goal, particularly in marginalized communities where disparities persist. Community-based public health research holds promise in addressing these inequities, but barriers to data access hinder its potential impact. This paper advocates for a paradigm shift towards more inclusive and equitable approaches to data access and utilization after community-based research. By implementing a research data access registry process, we can overcome existing barriers, promote transparency, and empower communities to leverage research findings for their benefit. This paper discusses the potential impact of this approach in promoting health equity, addressing health disparities, and fostering trust in minority communities. Beneficiaries include doctoral students, post-doctoral researchers, community health centers, pharmacies, and medical centers interested in accessing data from community-based public health research to create toolkits, inform evidence-based practices, and recommend better patient-reported outcomes treatment approaches.

KEYWORDS: community-based research, data access, public health research mistrust, transparency, accountability, community engagement, research ethics, data sharing, marginalized communities, clinical trials

Introduction

Several significant historical instances of unethical human research practices, especially involving vulnerable populations, have greatly influenced public trust in research, researchers, and science (Huff et al., 2023). Notably, the U.S. Public Health Study of Untreated Syphilis with Black men in Tuskegee, Alabama, and the unauthorized use of Mrs. Henrietta Lacks' cells by Johns Hopkins Hospital stand out. Despite profoundly shaping U.S. research ethics regulations, these events continue to impact public willingness to participate in clinical trials and research, particularly among African Americans and rural communities (Huff et al., 2023).

The apprehension towards potential ill-treatment, mistreatment, and uncertainties associated with involvement in clinical trials, particularly large pharmaceutical corporations, healthcare providers, and institutions, has been extensively examined as significant barriers hindering minority participation (Clark et al., 2019). Specifically, the fear of being perceived as a "guinea pig" or a subject in an experimental study has been identified as a major deterrent for minorities considering participation in clinical trials (Clark et al., 2019). The historical mistreatment of minority individuals, including prisoners and military personnel, has left a lasting negative impact on perceptions of clinical research within ethnic communities (Farr et al., 2015).

Due to enduring mistrust within the American healthcare system, certain African Americans in the United States exhibit hesitancy toward receiving COVID-19 vaccinations (Elliott, 2021). This distrust finds its roots in historical events, notably the infamous syphilis research project conducted in the United States, which egregiously violated the rights of African-American males by withholding treatment for the disease for the sake of medical experimentation (Elliott, 2021). As a result, African Americans familiar with this study are engaging in discussions regarding the deployment of the COVID-19 vaccine (Elliott, 2021). The COVID-19 pandemic, along with its disproportionate impact on communities of color, has underscored the deficiencies within the United States healthcare delivery system (Elliott, 2021).

In the United States, pursuing a fair and equitable healthcare system accessible to all citizens remains a focal point of contemporary political discourse (Yearby, 2018). However, access to healthcare in the U.S. is not uniform and is influenced by various factors such as race, ethnicity, age, sex, socioeconomic status, disability status, sexual orientation, gender identity, and residential location (Huff et al., 2023). A culturally diverse healthcare system is essential for improving access to healthcare, addressing unmet health needs, reducing preventable diseases, and alleviating financial burdens on underserved populations (Huff et al., 2023). Culturally competent healthcare, accompanied by culturally inclusive healthcare research, is imperative to ensure that all ethnic groups receive tailored healthcare services (Dawes, 2019). This approach should prioritize effective medical treatments and personalized disease prevention strategies (Dawes, 2019). Therefore, achieving healthcare for all necessitates the inclusion of a diverse array of research participants across all stages of healthcare research. Specifically, clinical research trials must adapt to demographic changes to generate scientific evidence demonstrating the effectiveness of healthcare interventions across different ethnic groups (Huff et al., 2023).

Throughout U.S. history, minority individuals have resisted voluntarily enrolling in clinical trials or opted out (Durant et al., 2014). Efforts have been made to enhance minority participation in healthcare and pharmaceutical research by implementing various research recruitment strategies (Hamel et al., 2016).

However, despite these initiatives, there has been minimal progress in increasing minority recruitment (Oh et al., 2015). The underrepresentation of minority groups in clinical trial participation has significant implications, as large segments of the U.S. population receive medical treatments that have not been adequately tested or are at risk of experiencing healthcare complications due to ineffective medications and treatments (Huff et al., 2023).

In the United States, clinical trials have consistently enrolled a disproportionately low number of minority participants compared to white individuals. Despite the increasing minority population rates in the U.S., minorities represent less than 10 percent of clinical trial participants (Clark et al., 2019). Research by Ramamoorthy et al. (2015) examined 167 new molecular compounds approved by the FDA between 2008 and 2013, revealing that one in five of these drugs exhibited varying response rates across ethnic and racial groups. Consequently, a pressing need remains to emphasize the importance of the continued inclusion of minorities in clinical trials.

Research incorporating concepts of race and ethnicity can advance not only public health but also clinical care, health care, and medical science (Bhopal, 2008; Quinn, 2021). Nevertheless, researchers and practitioners need to be aware of the broader events of health improvement that are needed, particularly among African Americans (Bhopal, 2008; Wedge, 2020; Ndugga et al., 2022). Due to the distrust within the medical system, healthcare practitioners must be aware of the risks associated with providing healthcare to minority groups in public health (Bhopal, 2008; Quinn, 2021). Intentionally focusing on "doing good" should be the goal, regardless of the individual's racial or cultural background (Bhopal, 2008). Showing kindness toward members of underrepresented ethnic groups is inconsistent throughout time or across demographics (Bhopal, 2008; Quinn, 2021). According to Bhopal (2008), doing good means that enhancing the health and care of ethnic groups should be an absolute necessity and not require any particular attention or a feeling of justice (Bhopal, 2008).

The recent SARS-CoV-2 pandemic has contributed to further erosion of public trust, disenfranchisement of communities' unwillingness to participate in research, and this further erosion has shown itself in racial/ethnic and rural communities' disproportionately lower participation in vaccine research and vaccination adoption (Huff et al., 2023). Misinformation, perpetuated by leading scientists, political leaders, community leaders, and others, demonstrated the weaknesses in communicating science and research in plain language. The novel nature of the SARS-CoV-2 virus also resulted in frequent changes to recommended public health measures and reports of vaccine efficacy but lacked the needed transparent communication to the public who would benefit from such interventions and information (Huff et al., 2023).

Clinical studies refer to research using human participants to add to the available medical knowledge (Allison et al., 2022). The two primary types of clinical studies include clinical trials (interventional studies) and observational studies (Allison et al., 2022). In clinical trials, participants are given specific interventions, such as drugs or devices, procedures, or modifications in the participants' behavior (Allison et al., 2022). Participation in clinical trials allows participants to play an active role in their own health, gain access to new research treatments, increase their options for treatment when the available options have failed, obtain expert medical care at leading health facilities during the trial, and contribute to the advancement of medical knowledge (Allison et al., 2022).

An essential consideration in the design of health research studies is the delicate balance between the risks associated with participation and the potential benefits to society and individual participants. The Belmont Report (National Commission for the Protection of Human Subjects, 1978) is a foundational document guiding ethical research practices, emphasizing respecting participants' autonomy and ensuring their informed consent throughout the research process. Central to the Belmont Report is the recognition of participants' fundamental right to make voluntary decisions regarding their participation in research and the ethical treatment of participants throughout the study.

Problem Statement

Despite the critical role of clinical trials in advancing medical innovation, recruiting participants for trials is arduous (Allison et al., 2022). Currently, African Americans only make up 15% of the minority participants in clinical trials. Likewise, Hispanics make up 7.6% of research participants (Allison et al., 2022). In 2020, research provided an overview of the demographic characteristics of participants in clinical trials for drugs (Allison et al., 2022). As per the analysis, the participation in clinical trials by subpopulation for new molecular entities and therapeutic biologics approved in 2020 was 56% females, 75% Whites, 8% Black African Americans, 6% Asians, 11% Hispanics, 30% age 65 and older, and 54% of the participants were in the United States (Allison et al., 2022). The results indicated an increase in female participation in clinical trials. However, the ethnic diversity of participants in clinical trials remained low. Understanding the factors impeding participation in clinical trials is critical, as successful trials must represent the population (Allison et al., 2022). With the development field of pharmacogenomics, it is essential to have a diverse study group. Thus, patient recruitment and retention are essential for deriving conclusive results from the clinical trial that may reflect the broader population (Allison et al., 2022). Community-based participatory programs have shown promise in creating more inclusive clinical trial representation (Wallerstein & Duran, 2010).

Community-based public health research has the potential to be a powerful tool for addressing health inequities, particularly in underserved communities. However, a persistent and ethically troubling pattern undermines this promise, which occurs when researchers often enter marginalized communities, collect data for a limited period, and disengage once the study concludes, frequently without sharing findings or maintaining any long-term commitment. This phenomenon, sometimes referred to as "helicopter research" or "parachute science," reflects a fundamentally extractive model of knowledge production that prioritizes academic outputs over community benefit.

In this model, communities, often those already burdened by structural inequalities, are treated as data sources rather than as partners in the research enterprise. Researchers arrive with predefined agendas, collect valuable personal, behavioral, or environmental data, and depart once their objectives have been met, taking with them the information and insights generated. Frequently, community members are not informed of the study's results, much less involved in interpreting them or using them to inform local action. The knowledge produced, instead of being leveraged to improve conditions within the community, is often published in academic journals that are inaccessible to the very people who contributed to the work. This pattern is not only ethically problematic but also counterproductive. It violates key principles of respect, justice, and reciprocity that should guide any engagement with vulnerable populations. When communities do not see tangible outcomes or benefits from research, trust is eroded. Residents may feel used or misled, reinforcing a legacy of skepticism and resentment toward researchers and institutions. This dynamic makes future collaboration more difficult and can significantly reduce participation in subsequent studies, particularly those that aim to address complex public health issues requiring sustained community engagement.

Moreover, the failure to return results deprives communities of the opportunity to act on potentially life-altering information. For instance, if a study uncovers high rates of lead exposure or identifies barriers to chronic disease management, not communicating those findings in a timely and accessible manner can delay interventions and perpetuate harm. It also prevents community members from using the data to advocate for resources, policy changes, or new programs tailored to their needs.

In contrast, ethical and effective community-based research demands ongoing relationships, transparent communication, and a commitment to long-term impact. This includes building capacity within communities, co-developing research questions, sharing findings in accessible formats, and ensuring that data is used to inform local decision-making and policy advocacy. Without these practices, public health research risks perpetuating the very inequities it seeks to address, leaving communities not only underserved, but also unheard.

Method

This paper employs a perspective approach. Perspective papers serve as a vital genre of academic literature, frequently employed in the humanities and social sciences, to offer provocative arguments, practical recommendations, and viewpoints aimed at challenging established perspectives and prompting readers to reevaluate specific issues (Shankar & Alshakka, 2021). These articles are characterized by their ability to provoke thought and stimulate intellectual discourse within a given field. The primary objective of a perspective paper is to encourage critical thinking and spark discussions among scholars, practitioners, and the broader audience, ultimately contributing to the ongoing development of ideas and the evolution of thought within a particular discipline. These articles challenge established norms and paradigms, inviting readers to question prevailing assumptions and re-examine their own beliefs and perspectives (Shankar & Alshakka, 2021).

The Aim of this Inquiry

Mistrust toward the scientific community, research institutions, and healthcare systems presents significant challenges for community-based research (CBR) initiatives. Despite efforts to foster trust through collaborative approaches, post-study obligations, and limited data access continue to hinder the potential benefits of research for communities, particularly among marginalized populations such as African Americans. Health disparities persist in marginalized communities, highlighting the urgent need for innovative approaches to promote health equity. Community-based public health research is a promising strategy to address these disparities. However, more data access would allow the translation of research findings into actionable interventions. This paper proposes a paradigm shift towards more inclusive and equitable data access and utilization approaches, emphasizing the potential impact on health equity, disparities, and community trust. This paper argues for an expanded approach to CBR data access, encompassing a research data access registry process for community members that participate in community based public health research. By implementing such a process, we can address existing barriers, promote transparency, and maximize the utility of research data for community benefit.

Novelty of the inquiry

This paper advocates for an expanded approach to CBR data access for community members that participate in the research. This advocates for adopting a research data access registry process to overcome existing barriers and maximize the utility of research data for community benefit. While previous research has recognized the importance of data access in promoting health equity and addressing disparities, the proposed paradigm shift towards more inclusive and

equitable data access represents a novel contribution to the field. By highlighting the potential impact of this approach on promoting health equity, addressing disparities, and fostering trust in minority communities, this conversation offers insights into innovative strategies for enhancing the effectiveness of community-based public health research. Moreover, this conversation extends the discussion beyond theoretical frameworks by providing practical examples of how various stakeholders, including doctoral students, post-doctoral researchers, community health centers, pharmacies, and medical centers, can benefit from improved access to community-based public health research data. These stakeholders can utilize such data to develop toolkits, inform evidence-based practices, and recommend better patient-reported outcomes treatment approaches, thereby enhancing the relevance and impact of research efforts on community health outcomes.

Community-Based Participatory Research Program (CBPR)

The issue of health disparities, particularly the underrepresentation of African Americans in clinical trials, presents a significant crisis with profound implications for equitable healthcare access and outcomes (Webber-Ritchey & Lane-Cordova, 2021). However, within this crisis lies the potential for transformative innovation and solutions. Addressing this disparity necessitates the development of creative and inclusive strategies to engage underrepresented populations in clinical research (Webber-Ritchey & Lane-Cordova, 2021). Innovative approaches such as Community-Based Participatory Research Programs (CBPR), culturally sensitive recruitment methodologies, and enhanced education and outreach initiatives can serve as effective means to bridge the gap in representation (Wallerstein & Duran, 2010; Baquet, 2012; Baquet et al., 2013).

Building upon this foundation, Mullins et al. (2012) introduced a comprehensive 10-step patient engagement framework to guide the Patient-Centered Outcomes Research (PCOR) process and delineate the purpose of engagement at each stage. This framework advocates for collaborative interventions involving scientific researchers and community members to address diseases and conditions disproportionately affecting populations experiencing health disparities (Mullins et al., 2012). By recognizing the unique strengths of each partner, scientific researchers from diverse disciplines and community members collaborate across all facets of the project, including needs assessment, planning, research intervention design, implementation, evaluation, and dissemination of community-level interventions (Mullins et al., 2012). Through this collaborative approach, the community is positioned as an equal partner alongside scientists in the CBPR program, ensuring that interventions developed are responsive to the community's specific needs (Mullins et al., 2012).

Allowing participants in community-based public health research to access the data and results after the study concludes offers a range of ethical, scientific,

and practical benefits. These benefits extend beyond individual empowerment to broader improvements in public trust, community engagement, research quality, and health outcomes. Below is a detailed examination of these benefits:

1. Ethical and Democratic Accountability

Respect for Persons and Autonomy
Providing participants with access to data and results respects their autonomy and acknowledges their contribution. Informed consent is not merely a procedural formality but a commitment to ethical reciprocity. Returning results affirms participants' role not just as subjects but as stakeholders in the research process.

Transparency and Trust
Transparency fosters trust between researchers and communities. When participants see that their data is not sequestered within academic silos but used to generate meaningful insights, and that these insights are shared, it promotes a culture of openness. This trust is essential for longitudinal partnerships and future research endeavors.

2. Empowerment and Community Capacity Building

Health Literacy and Self-Efficacy
Disseminating results in accessible formats enhances community health literacy. Understanding local patterns of disease prevalence, risk factors, and effective interventions equips individuals and organizations to make informed health decisions and advocate for systemic change.

Collective Agency
Access to data enables communities to take collective action based on evidence. For example, if research identifies high levels of environmental toxins in a neighborhood, residents can use that data to lobby for policy interventions or resource allocation.

3. Improved Relevance and Applicability of Research

Participant Feedback Loops
When communities are granted access to data and outcomes, they are more likely to provide valuable feedback, critique interpretations, and highlight contextual nuances that researchers might overlook. This feedback can inform future research design, improving ecological validity and cultural sensitivity.

Tailored Interventions
Communities with access to disaggregated data can develop tailored interventions aligned with their specific needs, rather than relying on generalized public health strategies that may not be applicable or effective locally.

4. Data Justice and Equity Considerations

Reversing Extractive Practices
Historically, public health research, especially in marginalized communities, has operated through extractive models where data is taken without reciprocal benefits. Sharing results disrupts these patterns and aligns with principles of data justice by redistributing informational power.

Equitable Knowledge Production
Inclusion in the knowledge lifecycle, from data generation to interpretation and application—helps democratize research. Communities transition from being mere subjects of study to co-producers of knowledge, with the authority to challenge dominant narratives and advocate for their lived realities.

5. Strengthening Public Health Infrastructure

Community-Led Monitoring and Evaluation
Communities equipped with research data can monitor the implementation and effectiveness of public health interventions. This local oversight enhances accountability and ensures that programs remain responsive to changing conditions.

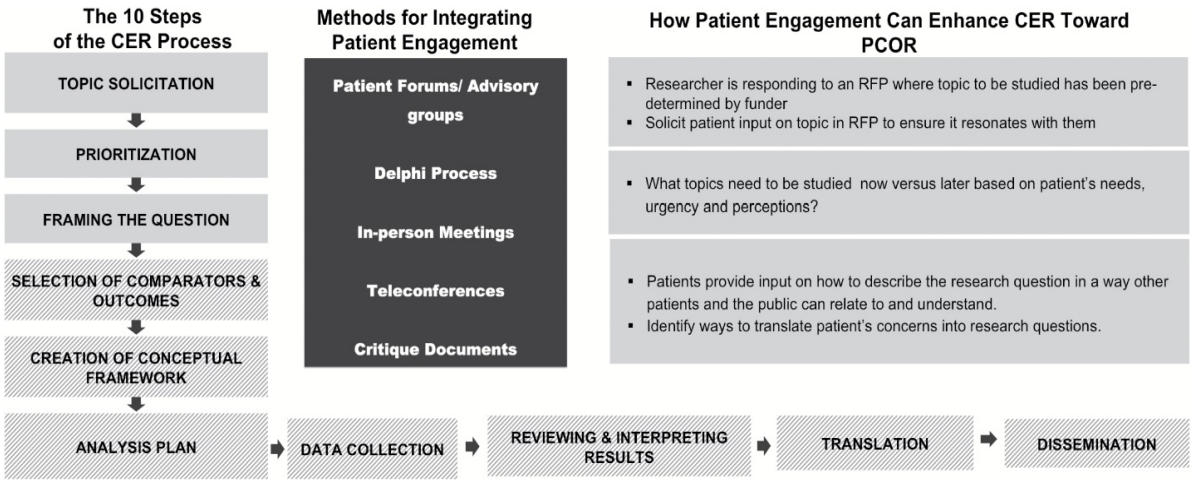
Sustainable Public Health Impact
When communities understand and own the knowledge generated, the sustainability of health interventions improves. People are more likely to maintain behaviors, programs, or coalitions when they see their relevance, efficacy, and rootedness in local evidence.

6. Ethical Precedent and Future Policy Influence

Setting Normative Standards
Normalizing participant access to data sets a positive precedent for ethical research conduct. It can influence funding agencies, institutional review boards (IRBs), and policy makers to embed these principles in guidelines and protocols.

Informing Broader Policy Agendas
Community interpretation of findings can also contribute to policy advocacy. Local narratives, supported by empirical evidence, can catalyze changes in regional health policy, environmental regulations, or urban planning.

By incorporating these elements and leveraging their advantages, the 10-step patient engagement framework to guide community-engaged research can lead to more meaningful, relevant, and impactful outcomes for healthcare researchers and their communities (Mullins et al., 2012).



Source: Mullins et al., (2012)

Benefits of Expanded Community-Based Research Data Access

Expanding access to research data offers numerous benefits for both researchers and communities. Firstly, it enhances transparency and accountability, fostering trust and confidence in research endeavors. Secondly, it enables communities to access and utilize research findings for their own benefit, empowering them to address local challenges and inform decision-making processes. Additionally, it promotes the ethical principle of reciprocity, ensuring that communities receive tangible benefits from participating in research initiatives. Moreover, expanded data access facilitates ongoing collaboration and knowledge exchange between researchers and community stakeholders, driving innovation and advancing scientific inquiry.

Advantages of a Research Data Access Registry Process

The proposed research data access registry process offers several advantages over traditional data management practices. Firstly, it provides a secure and centralized database for storing research data, ensuring compliance with data protection regulations and safeguarding participant confidentiality. Secondly, it establishes clear requirements for accessing research data, including completing HIPAA and Responsible Conduct of Research Training, thereby promoting ethical research practices and data stewardship. Moreover, it facilitates efficient and transparent data-sharing processes, enabling researchers and community members to access and utilize research data for future exploration and benefit.

Promoting Health Equity Through Inclusive Data Access

Expanding access to research data can significantly contribute to advancing health equity by facilitating the development of evidence-based interventions tailored to the needs of marginalized communities. Researchers, including doctoral students and post-doctoral researchers, can leverage accessible data to conduct impactful

studies that address health disparities and promote health equity. Furthermore, community-based health centers, pharmacies, and medical centers can utilize research findings to inform the development of evidence-based practices and interventions to improve health outcomes and address unmet community needs.

Addressing Health Disparities Through Ethical Data Utilization

Ethical data utilization is essential for addressing health disparities and promoting trust in minority communities. By implementing a research data access registry process, researchers can ensure compliance with ethical standards and protect the rights and confidentiality of research participants. Transparent data-sharing processes foster trust and collaboration between researchers and community stakeholders, ultimately enhancing the relevance and impact of research efforts in addressing health disparities.

Empowering Communities Through Transparent Collaboration

Transparent collaboration between researchers and community stakeholders is critical for empowering communities to leverage research findings for their own benefit. Allowing participants in community-based public health research to access the data and results after the study concludes offers a range of ethical, scientific, and practical benefits. These benefits extend beyond individual empowerment to broader improvements in public trust, community engagement, research quality, and health outcomes. A research data access registry process promotes collaboration, transparency, and accountability in research endeavors, enabling communities to actively participate in the research process and shape interventions that address their unique needs and priorities. By fostering a culture of inclusivity and equity, this approach strengthens community trust and promotes sustainable improvements in health outcomes.

Key Elements of the Research Data Access Registry Process

Based on the information provided, here are some policy recommendations and actionable steps that health research funders and policymakers can take to ensure informed consent and ethical use of community public health research data:

Establishment of Secure Database Infrastructure

Health research funders and policymakers should prioritize establishing a secure database infrastructure capable of storing and managing research data in compliance with relevant regulatory standards. This infrastructure should incorporate robust security measures to safeguard sensitive data and protect against unauthorized access or breaches.

Mandate Training on Data Ethics and Security

Health research funders and policymakers should mandate that individuals seeking access to research data undergo data ethics and security training, including completing HIPAA and Responsible Conduct of Research Training. This training ensures that individuals understand their responsibilities in handling research data ethically and in accordance with established guidelines.

Promotion of Community Engagement and Collaboration

Health research funders and policymakers should encourage and incentivize community engagement and collaboration in research endeavors. This additional layer of community support includes actively involving community stakeholders in designing, implementing, and evaluating research projects and promoting inclusivity and equity in data access and utilization.

Implementation of Research Data Access Registry Process

Health research funders and policymakers should support adopting a research data access registry process to overcome existing barriers and maximize the utility of research data for community benefit. This process should facilitate transparent and accountable data access while protecting participant privacy and confidentiality.

Support for Practical Implementation and Dissemination

Health research funders and policymakers should provide the community with additional resources and support for the practical implementation and dissemination of research findings derived from community-based public health research. This includes funding for the development of toolkits, evidence-based practices, and better patient-reported outcomes treatment approaches that can directly benefit community health outcomes.

Monitoring and Evaluation

Health research funders and policymakers should establish mechanisms for monitoring and evaluating the effectiveness and impact of policies and initiatives to ensure informed consent and ethical use of community public health research data. This includes ongoing assessment of data access processes, stakeholder engagement strategies, and adherence to ethical standards.

By implementing these policy recommendations and actionable steps, health research funders and policymakers can help ensure that community public health research data is used ethically and responsibly while maximizing its potential to benefit community health outcomes. A paradigm shift towards more inclusive and equitable approaches to data access and utilization after community-based public

health research can significantly impact health equity, address health disparities, and foster trust in minority communities. By implementing a research data access registry process, we can overcome existing barriers, promote ethical research practices, and empower communities to leverage research findings for their own benefit. This conversation underscores the importance of collaboration, transparency, and accountability in research endeavors, emphasizing the transformative potential of inclusive data access in advancing health equity.

Recommendations for Future Research

This paper advocates for an expanded approach to community-based research (CBR) data access, emphasizing adopting a research data access registry process to address existing barriers and maximize the utility of research data for community benefit. While the proposed paradigm shift represents a novel contribution to the field, further research is warranted to explore and evaluate various research methods that can effectively implement this approach and assess its impact on promoting health equity, addressing disparities, and fostering trust in minority communities.

Action Research

Action research offers a participatory approach that empowers communities to engage in the research process and actively drive meaningful change. Future research should explore the application of action research methodologies in implementing the proposed research data access registry process within diverse community settings. Steps involved in action research may include:

- Collaborative problem identification and prioritization with community stakeholders.
- Co-designing and implementing the research data access registry process.
- Iterative cycles of data collection, analysis, and reflection to inform ongoing improvements.
- Action planning and implementation of interventions based on research findings.

The advantages of action research include its ability to foster community ownership, promote sustainable solutions, and facilitate the co-creation of knowledge between researchers and community members.

Narrative Inquiry

Narrative inquiry offers a qualitative research method that explores individuals' stories and experiences within a specific context. Future research could utilize narrative inquiry to capture community members' lived experiences and perspectives regarding data access and utilization in community-based public health research. Steps involved in narrative inquiry may include:

- Conducting in-depth interviews or focus groups with diverse community members.
- Collecting and analyzing narratives to identify common themes and patterns.
- Engaging in reflexive analysis to interpret and contextualize the narratives within broader social, cultural, and historical contexts.
- Generating insights and recommendations for improving data access and utilization processes.

Advantages of narrative inquiry include its ability to provide rich, contextually embedded data, promote participant voice and agency, and offer nuanced insights into complex social phenomena.

Focus Group Qualitative Research

Focus group qualitative research involves facilitated group discussions among participants with shared characteristics or experiences. Future research could utilize focus group methodologies to explore stakeholders' perceptions, attitudes, and preferences regarding implementing a research data access registry process. Steps involved in focus group qualitative research may include:

- Recruiting diverse stakeholders, including community members, researchers, and healthcare professionals.
- Facilitating structured discussions around key topics related to data access and utilization.
- Analyzing group interactions and dynamics to identify common themes and perspectives.
- Generating actionable recommendations for optimizing the design and implementation of the research data access registry process.

The advantages of focus group qualitative research include its ability to capture diverse perspectives, stimulate group dialogue and interaction, and generate insights that may not emerge through individual interviews or surveys.

By employing these research methods, future studies can deepen our understanding of the implementation and impact of a research data access registry process in community-based public health research. Such research efforts are essential for advancing knowledge, informing evidence-based practices, and ultimately improving health outcomes and promoting equity within marginalized communities.

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