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Applying a research ethics review processes in rural practice-based research

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Applying a research ethics review processes in rural practice-based research

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Abstract

Introduction

Partnering with rural primary care in practice-based research allows researchers access to a vital segment of the health care sector and a window into some of the most vulnerable, high-risk, high-need patient populations. The readiness for rural primary care to fully embrace research partnerships, however, is often tempered by ethical questions in conducting research in close-knit settings. This research provides practices with a refined decision support tool for evaluating the fit of research opportunities for their unique practices.

Materials and Methods

A two-phase effort was conducted to glean insight from currently available literature on ethical considerations in practice-based research and augment this information by consulting with state-based subject matter experts. Qualitative data were gathered through semi-structured interviews with key stakeholders at each of the West Virginia medical schools.

Results

The literature clearly acknowledges the need to ensure ethical standards in practice-based research – from the standpoints of the clinician and the researcher. The need to ensure comprehensive, culturally appropriate institutional review board approval is essential in developing and safeguarding participants. From discussions with subject matter experts, we find complementary guidance. However, tempering this sentiment is an overall caution regarding the unique role of rural primary care in representing and protecting the needs of the community. Five fundamental cautions regarding the conduct of practice-based research in rural settings are here identified, spanning the protection of individual patients, their communities, and clinicians.

Discussion

Findings from this study can support and empower primary care clinicians and practices, especially those in rural and close-knit communities, to address essential considerations in practice-based research. Results allow for framing of a refined decision support tool for primary care practices and clinicians to use in evaluating the fit of research opportunities for their unique practices, instilling a sense of shared power in the research process by better equipping primary care to proactively engage in substantive dialogue with research partners.

Keywords

ethics, practice-based research

Introduction

Primary care is integral to the health and wellbeing of our nation, and to the vitality of rural states such as West Virginia.^{1,2} By design, primary care practices care for patients who are at times underserved, reside in geographically isolated locations, and often have complex health

care needs. All the while, primary care practices do this work in a manner that promotes not only patient-centered but also cost-effective care.³ In rural states like West Virginia, primary care is a front-line defense in combatting the opioid crisis, rampant chronic health conditions, mental and behavioral health complexities, and health issues faced by an aging population.⁴ Further, the health care teams at these practices are adept at balancing delicate roles – serving as a patient’s medical home while at the same time being friends, neighbors, and even family in close-knit, rural communities.

Given the dynamic nature of rural primary care and its prominent role in addressing health care and health disparities, rural primary care practices have become an attractive venue for practice-based research. It is well demonstrated that layering-in research in the primary care setting offers benefit to both health system quality of care efforts and patient outcomes.⁵⁻⁷ However, the salient, unique nature of rural primary care and the ethical questions concerning research in smaller, rural settings deserves exploration.⁸ Ensuring direct benefit from research to the community and primary practice, and establishing leadership of primary care in the research process are essential. Further, addressing concerns over the impact of research on a community’s reputation, questions of patient privacy and protections, and legal and ethical concerns over patient data access, security and sharing are prerequisite to establishing a long-term, engrained practice-based research presence. Shore et al expresses these sentiments well in their examination of community-engaged research procedures and their guidance in empowering communities to leverage review procedures sensitive to and informed by community needs.⁹ Highlighting essential considerations such as communities benefitting directly from the research, having substantial engagement in the research process including agenda setting, and understanding potential risks, the authors provide pragmatic advice applicable to practice-based research needs in rural primary care.

This study aims to operationalize available literature on ethical considerations in rural practice-based research, including the work of Shore et al⁹, and supplement this knowledge with direct input from local-level experts in research ethics. The goal of this work is the development of a research review tool whereby primary care teams, administration, and leadership can review available research opportunities and gauge the fit of those opportunities for their practices.

Materials and Methods

The West Virginia Alliance for Creative Health Solutions (WVACHS)¹⁰, a practice-led research and advocacy network formed in 2014, initiated efforts to provide guidance to rural primary care on essential considerations in pursuit of practice-based research. Basing efforts on the work of Shore et al⁹ in their examination of community engaged research, the WVACHS conducted a two-phase effort to glean insight from currently available literature on ethical considerations in practice-based research and augmented this information by consulting with state-based experts in research ethics. These supplemental qualitative data were gathered through three separate hour-long, face-to-face interviews with subject matter experts (SMEs) at each of the state’s three medical schools (Marshall University, West Virginia School of Osteopathic Medicine, and West Virginia University). These interviews were conducted during the spring of 2015 by members of the research team. SMEs were identified by the research team based on their roles in the research review processes and in their application of ethical procedures in research at each medical

school. Two medical ethics instructors and one institutional review board director were identified for interview.

Using a semi-structured interview format developed through an iterative process of drafting and consensus building by WVACHS leadership and the research team, each SME was asked to: 1) share his or her perspectives on major ethical issues and considerations in conducting practice-based research in rural primary care; and 2) provide their guidance in developing a tool whereby rural primary care partners can evaluate research proposals and gauge the fit of those proposals for their practices. SMEs were interviewed by three study personnel, with notes taken by each study personnel independently. Notes were then compared for accuracy and consistency. Following a grounded theory technique to qualitative research,^{11,12} a combined inductive approach to content analysis, allowing for patterns and themes to emerge from the data, and directed content analysis were used in reviewing the data and identifying mutually agreed-upon themes. These themes serve as the basic tenets or findings from the discussion. Next, synthesis of the data into key constructs was conducted with a final review of all results by key study personnel. These constructs, born from the more general themes, afford specificity to the analysis and clear meaning to the findings. This work received West Virginia Institutional Review Board approval (protocol number 1806147914).

Results

In-person interviews with one SME from each of the state's three medical schools yielded rich context for more closely considering ethical considerations in rural practice-based research – particularly among West Virginia health systems. Two medical ethics instructors and one institutional review board director were interviewed, achieving our goal of reaching a SME at each institution.

From discussions with SMEs, we find complementary, supporting guidance as found in the literature. The experts agreed that practice-based research can promote improved health outcomes in primary care. However, tempering this sentiment is an overall caution regarding the unique role of rural primary care in helping to represent and protect the needs of the community. This vital concept was woven through discussions, available literature and research team consensus, manifesting in the following fundamental cautions regarding the conduct of practice-based research in rural settings.

- While institutional review boards are charged with protecting individual patient privacy, also of significant concern is protecting the reputation, perceived character, and public opinion of the patient, clinician, practice, and community. If protections are absent or weak, one or more parties may be disinclined to participate and even harmed if participating.
- A patient considering sharing personal data or biological specimens for research must be equipped and empowered to weigh the risks and benefits of participation – not simply in light of protecting personal health information but also his or her identity in the community.
- The request to participate in research exceeds the usual social contract between clinician and patient, as research often asks the patient to share information that goes

- beyond what is needed for treatment. Without clear understanding of the research, these requests can strain the trust built over time between patient and clinician. The trust that the patient places in the clinician is essential to the viability of the practice and, at times, to the health of a community.
- The clinician and practice, because of their integration into a close-knit community, also have a responsibility to protect the identity of the community itself. A research paper that does not portray the humanity of a community and focuses solely on its negative characteristics can affect the trust and identity of the clinician or practice that supported the research. For example, Appalachian communities, which are often characterized as obese, uneducated, addicted to opioids, and riddled with chronic diseases may be particularly sensitive to how they are portrayed in a published report. When a clinician or practice in a close-knit community invites a patient to participate in research, the clinician or practice is seen by the patient as vouching for the value of the research. Clinicians and practices that are cognizant of this dynamic can use their identity in the community to advocate for participation in research that has the potential to benefit their patients and the community. Conversely, clinicians and practices that do not protect the identities of their patients and communities may find that their reputation in the community suffers and that patients are unwilling to participate in future studies.
 - The clinician or practice should be an active partner in the design, implementation, and dissemination of research efforts. Prior to committing to a project, a clinician or practice should formally review the proposed effort and confirm it is meaningful to the community and apt to inform local practice and policy change. Additionally, a practice should have a memorandum of understanding with the researcher that establishes clearly defined roles, responsibilities, and the intent of the research prior to entering a practice-based research effort.

To support rural primary care practices and clinicians in making well-informed decisions regarding participation in practice-based research, the WVACHS recommends use of an evaluation tool (Figure 1) whereby primary care practices can consider research opportunities in light of the essential considerations here identified. This tool, stemming from research led by the work of Shore et al⁹, guidance provided by SMEs interviewed, and final consensus building and drafting by the WVACHS, provides a pragmatic means for empowering primary care partners in addressing priority concerns. In summary, this tool outlines ten essential considerations and provides the primary care practice with the opportunity to consider each and then make an overall recommendation on whether or not to proceed with the practice-based research effort.

Figure 1. Evaluation Tool for Primary Care Participation in Research

Practice:

Policy Title:

Policy Manual:

Effective Date:

Approved by Board of Directors Date:

Purpose: The practice will enter into research only after careful consideration of the benefits and risks to the practice, patients, and community. The following tool presents key criteria for determining whether or to not participate in a research effort. All potential research will be reviewed by an administrator with the authority to act in the practice’s name. The review may include the input of practice stakeholders such as health care team members with relevant expertise and patients with unique insight into aspects of the proposed research.

Procedure: Please review the following criteria¹ and mark **Yes** or **No** as appropriate. Once complete, please review the results with appropriate stakeholders and note the final decision within the Recommendation section at the close of the tool. Provide any additional information as needed in documentation appended to this form.

Title of proposed study:

Research Evaluation Criteria	Yes	No
1. The practice is able to commit resources to evaluate, coordinate and complete the proposed research.		
2. The research is meaningful and aligns with the mission of the practice.		
3. The research will potentially benefit the practice’s service community.		
4. The research has a low risk of harm to the practice or service community.		
5. There are concrete plans to share findings with the practice at large and the community it serves.		
6. The research will use culturally appropriate methods, including recruitment and consent strategies.		
7. The practice costs to participate (time, staff, disruption to work flow, etc.) will be compensated.		
8. The practice will have a signed memorandum of understanding detailing the research.		
9. The research findings will be amenable to translation into practice or policy change.		
10. The proposed research project has undergone appropriate Institutional Review Board approval.		

Recommendation:

The evaluation tool provided here details the following areas:

- 1) the ability for the practice to commit resources to evaluate, coordinate, and complete the proposed research
- 2) the meaningfulness of the research and alignment with organizational mission
- 3) the potential benefit of the research to the community
- 4) a low risk of harm to the practice or community
- 5) plans for dissemination of research findings
- 6) use of culturally appropriate methods, including patient recruitment and consent
- 7) acknowledgment of practice costs of participating and compensation for those costs
- 8) signed research partnership agreement
- 9) ability to translate research findings into practice or policy change
- 10) written certification that the proposed project is either exempt from or has received institutional review board approval

Discussion

Guidance presented in this research is intended to support and empower primary care clinicians and practices, especially those in rural and other close-knit communities, to address essential considerations in the pursuit of practice-based research. Information gleaned through interviews with SMEs and by a current review of the literature has allowed for the framing of a refined decision support tool for primary care practices and clinicians to use in evaluating the fit of research opportunities for their unique practices and for ensuring the integrity of the community and practice is protected. From the literature, we find clear acknowledgment of the need to ensure ethical standards in practice-based research – from the standpoints of the clinician and that of the researcher.^{9,13-21} The dual relationships rural clinicians can have with their patients, being at the intersection of health care and health research, spurs questions of patient confidentiality and privacy²² especially in close-knit communities. Further, the need to ensure comprehensive, culturally appropriate institutional review board approval is essential in developing and safeguarding appropriate research protocol detailing priority issues such as patient/community consent and ensuring understanding of the full range of potential risks and benefits of proposed research.^{9,16} Having a well-informed patient population and a well-grounded team of clinicians and researchers acting in tandem are essential pieces of the research continuum.

While limited in scope, this study aims to spur further discussion into and careful consideration of the conduct of practice-based research in rural settings, and the need for not just practice-based but practice-led and informed research efforts. Taken as a whole, the review criteria presented here can help instill a sense of shared power in the research process by better equipping primary care to proactively engage in substantive dialogue with research partners. Further, this paper intends to help practices navigate research opportunities and proactively address concerns over critical issues such as risks and benefits of the research to the practice and community, which may otherwise prevent practice-based research from being a possibility in rural clinical settings.

Future efforts in exploring ethical considerations in rural practice-based research could involve a larger number of SMEs from each of the state's medical schools, and greater emphasis on evaluating the application of the research review tool provided here. Additionally, while this current version of the research review tool has no quantitative scoring criteria or cut-off points in terms of decision making, it is intended as a conversation piece for primary care leadership to carefully review and consider specific aspects of any given practice-based research effort and be able to use their own judgement and discernment to make the final decision on whether or not to participate. This current study aims to present a pragmatic decision support tool applicable for use by the primary care team and administration when considering the fit of any given practice-based research effort for their particular practice. While this tool is used by primary care membership within the WVACHS, a more broad-based testing with feedback is warranted for the tool's continued development and utility.

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