

A Community-engaged Approach to Research Translation: The CIPHERS Project

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ABSTRACT

Problem: Translating research to support practice is becoming a more prominent goal in the scientific community. However, further innovation and research is needed on effective approaches to this endeavor.

Purpose: This case study describes an approach that combines the insights of diffusion of innovation theory with the philosophy and practices of community engagement.

Key Points: Elements of our approach included staged dissemination, iterative active engagement, multi-pronged and tailored messaging, use of networks, contextualization of study findings, and emergent strategy. Our work proceeded in five stages, from laying the groundwork to deepened partnership.

Conclusion: Our experience illustrates the challenges and confirms the benefits of a community engaged, partnered, and non-linear approach to research translation aimed at improving public health.

KEYWORDS: Southeastern United States, Physician's Practice Patterns, Reproductive History, Sex Factors, Primary Prevention, Preventive Health Services, Public Health, Community health partnerships, Community health research

Translating research to support practice is an increasingly prominent goal in the scientific community. However, further innovation and research is needed on effective approaches to translation. This case study describes an approach that combines the insights of diffusion of innovation theory with the philosophy and practices of community engagement.

The Problem

Dissemination and translation of research to inform behavior change, practice, and policy is an increasing concern in the scientific community.¹ However, scientists struggle to effectively translate research into action.^{2,3} Despite evidence to the contrary, the predominant model of research translation in health is a linear one that assumes that exposure to research findings will compel professional, politicians, and the public to make changes.^{2,4} The assumption behind this model is that the key barrier to change is an information deficit,⁵ The model fails to recognize the complex reasons why individuals, organizations, policymakers, and societies might be prone to act towards or against change.^{2,3}

The gap between this linear model and reality is particularly large for public health. Ogilvie et al. note that public health involves a “fundamental and wide-ranging societal response” to complex health challenges.⁶ The need to translate scientific knowledge into public health practice is rarely solved by creating a single new clinical protocol. Rather, it requires increasing awareness and inspiring behavior change among clinicians, public health practitioners, policymakers, and the general public.

Moreover, public health sometimes requires learning from evidence of a variety of types and strengths. Many public health issues are ill-suited to the randomized control trials that constitute the gold standard for medical research. Randomization may not be feasible or ethical and the

causes of problems and their solutions may be multifaceted and intertwined.⁶ Thus, dissemination of this research must be nuanced and iterative.

Some scholars argue that community engagement is a critical corrective to the prevailing model of linear research translation. The Canadian Institutes of Health Research hold that translation requires effective exchanges between researchers and users, including partners from a variety of disciplines, the public, and the private sector.⁷ Similarly, dialogical models of research translation recognize that new knowledge results from interaction of researchers and stakeholders rather than unilateral dispersal of information.² Nonetheless, there is a paucity of case studies that help us understand what community engaged research translation looks like in action.

Purpose of Article

This paper explores one approach to community-engaged translation of research knowledge for population health improvement. The context is the Cannabis-Induced Potential Heritability of Epigenetic Revisions in Sperm (CIPHERS) Project at [BLINDED FOR PEER REVIEW], launched in 2017. CIPHERS studies if and how paternal preconception marijuana use can result in epigenetic changes (changes in how genetic material is expressed in the body), which may then be transmitted to subsequent generations. The research is ongoing, but early results indicate that marijuana use can alter sperm epigenetics, with animal studies showing associated changes in neurodevelopment and behavior in animal offspring.^{8,9, 10}

Our case context exemplifies several characteristics of public health research translation described in the literature: an issue with multiple potential policy and practice implications, a goal of knowledge transfer to a variety of audiences, early stages of scientific research, and the

inapplicability of the human subject randomized control trial. This case study describes how the CIPHERS Dissemination and Outreach team brought this important research to the larger community.

Key Points

Approach

Two bodies of literature inform our approach to outreach and education for CIPHERS. The first is Everett Rogers' work on diffusion of innovation. Rogers notes that diffusion of new ideas and ways of doing things does not depend solely on the facts;¹¹ rather, diffusion is the process of interaction among an innovation, communication channels, and the larger social environment over a period of time. Time operates in three ways. First, adoption of a new idea begins with exposure to the idea and ends with confirmed commitment to its utilization. Second, within a group, some people will be "early adopters" of an innovation while others only become interested later. Third, there will be a period of time before an innovation is adopted by a system.

The second body of literature informing our approach is that of community engagement, i.e., "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people."¹² The central insight of this literature is that communities are the experts on their own needs and assets and that involving communities in all aspects of research or health promotion can improve its relevance, validity, and community benefit. Community engagement promotes effective and sustainable translation of research into action by providing insight into

how to reach out to specific audiences in a specific context, creating relationships of trust, and promoting stakeholder buy-in to research.¹²⁻¹⁷

Community engagement can signify engagement with the group whose health is the target of a program of study, advocates for that community, and/or those who serve them. In the case of CIPHERS, our initial goal was to inform and influence the clinicians and public health professionals whose actions would in turn inform and influence the behavior of the public. As will be seen, our approach came to involve – in different ways and at different times -- three types of communities: clinicians, public health professionals, and the affected community, with the latter represented by community organizations such as a men’s health council that included members of the general public, a fraternal organization, etc.

Rooted in the literature on diffusion of innovation and community engagement, the framework for our research dissemination has the following elements:

- staged dissemination beginning with early adopters;
- iterative active engagement with target audiences;
- multiple and tailored messaging content;
- amplification of dissemination through evolving networks;
- ongoing contextualization of study findings;
- emergent strategy based on community engagement, audience feedback, adaptation to context, new opportunities

This case study illustrates how these elements were embodied in the stages of work of the CIPHERS outreach and dissemination team over the course of three years. Table 1 serves as a guide to the case study, listing the elements of our approach, delineating their origins in diffusion

of innovation theory and community engagement principles, and providing select examples of each element in practice for CIPHERS.

Stages of Work

Overview. The stages of our work are shown in Figure 1. Table 2 summarizes how community involvement in the work changed as we moved through these stages. We characterize community involvement using the seven-point community engagement in research continuum developed by Key et al, which moves from no community involvement at all to community-led research.¹⁸ However, in the context of this article, the points on the continuum do not refer to the entire research enterprise but only to the activity of translating or disseminating research findings.



Figure 1: Stages of the CIPHERS Outreach Approach

Some aspects of our evolving work were anticipated in advance, and -- as befits a stakeholder-engaged approach -- other aspects represent an organic evolution from the relationships we developed and the lessons we learned. We built formative evaluation into our work, including tracking social media metrics and surveying audiences at appropriate outreach events, which

netted us almost 400 surveys. This formal evaluation (a form of what Key et al call being community-informed, the least intensive approach to community involvement in research¹⁸ (Table 2)), together with lessons learned from speaking with stakeholders and reflection on our own practice, helped move us through the stages described here.

Stage 1: Laying the groundwork for diffusion. We began by creating a website to communicate about the study, and its findings, and to provide general information about marijuana policy and epigenetics. The website was designed for both lay and scientific audiences. It includes descriptions of the study, recruitment information, outreach activities, and a project blog. Publications have been added to this location on a rolling basis since the first paper on study findings was published in 2018. Outreach materials presenting these findings in lay terms can also be found on the site. Other efforts to make the site accessible for lay audiences included use of relatable language, provision of fact sheets describing the scientific background, and creation of a whiteboard-style animated video using everyday language to explain epigenetics. We also created social media channels on Twitter and Facebook to serve as avenues for dissemination of our work and to share regular research updates with target audiences. Social media channels also allowed us to engage in conversations and learn of developments related to our work that we may not have otherwise known about.

We were attentive to the fact that the body of research on marijuana and sperm epigenetics was in an early stage and that randomized control trials on humans were not an option. Nonetheless, we thought that it was important to share information that would allow informed reproductive health choices. We began a process that continued throughout dissemination of working closely with the research team to contextualize CIPHERS within other relevant research (including the

influence of other environmental exposures on sperm epigenetics) and to make sure that we were using language that was in line with the available evidence.

We were also attentive to two aspects of the larger context in which we were operating: false societal assumptions that marijuana users are predominantly racial/ethnic minorities and/or low-income, and the potential for others to believe that we were advocating against legalization of marijuana use. We were proactive in reaching out to diverse audiences and were careful to use racially/ethnically diverse imagery in our materials. We also made it clear that legalization of marijuana had potential benefits, such as preventing prison time for users and making marijuana available for medical treatment, but that legalization also presented new public health challenges. We wanted CIPHERS research to be part of the discussion of how to address those challenges.

Stage 2: Initial community engagement. Incorporating Rogers' insights into diffusion of innovation, we began targeted dissemination of CIPHERS findings with stakeholders whom we thought were likely to be "early adopters" because of a prior working relationship with a member of our study team and a clear stake in issues of reproductive or men's health.¹¹ This included clinicians working in fertility, family medicine, and obstetrics, and the local department of public health.

As shown in Table 2, we actively consulted with these stakeholders, sharing information and seeking to understand their thoughts and needs related to our work. Notably, we learned that while paternal use of marijuana was not yet on the radar of most health professionals, they were concerned about the rising use of marijuana among pregnant and breastfeeding women. Many clinicians and public health practitioners felt ill equipped to have evidence-based conversations

with patients/clients regarding marijuana use. This feedback led us to incorporate findings from existing research on maternal marijuana use during gestation and breastfeeding into our dissemination of information on paternal preconception marijuana use.

Our willingness to address stakeholders' priorities facilitated access to the audiences they represented and helped us to tailor our communication to those audiences. For example, we worked with clinicians to develop materials on maternal marijuana use for their pregnancy centering practice, which led to a presentation on maternal and paternal use for practitioners at the associated family medicine clinic. Despite maternal use being our "in" to the practice, post-presentation survey respondents most frequently cited the CIPHERS research on cannabis and sperm epigenetics as the most interesting thing they had learned.

Incorporating a secondary focus on maternal marijuana use also deepened our understanding of the implications of paternal use. We came to understand that maternal and paternal exposure to marijuana are intertwined through secondhand smoke and that one partner's choice can influence another's health. Finally, broadening our approach gave us access to new audiences. Audiences with a focus on maternal health could easily understand the relevance of our information on maternal cannabis use, and then came to understand the relevance of the material regarding paternal use.

Our process is also illustrated by our work with the Men's Health Council of our local public health department. As with other professionals we initially contacted, the coordinator of the council had previously worked with a team member. A meeting between this coordinator and that outreach team resulted in a plan to present CIPHERS and maternal health information at an upcoming council meeting. The CIPHERS outreach team was able to reach a highly relevant and

receptive audience already scheduled to meet, the council benefited from the content that the CIPHERS team delivered. Both community and public health attendees quickly requested additional dissemination from us (at a neighborhood organization meeting and health department staff trainings), moving us further along the engagement continuum to community participation (Table 2).

Stage 3 – Moving from engagement to partnership. Our experience in stage 2 highlighted how essential community engagement was in our process. We recognized that none of our team members represented the audiences we were trying to reach, and that greater stakeholder involvement in our work would provide us with deeper understanding of the kinds of materials and messages that would speak to those audiences. Moreover, having incorporated maternal marijuana use into our work, we needed somebody on the team who could address that subject.

We invited the director of the pregnancy centering program at the family medicine clinic to become a paid team member. Her work became critical as new opportunities to share information on maternal and paternal marijuana use were identified with increasing speed. Our partnership expanded further when a medical student with experience in reproductive health joined our team to complete a practicum for a master's in public health. She brought to the team a passion for reaching medical learners, knowledge of the best ways to do so, and relevant contacts. Her membership resulted in presentations at relevant meetings and training events. The incorporation of the physician and medical student enhanced community participation in our research translation efforts (Table 2). It is important to note that this new step included only clinical professionals. Moreover, the formal leadership structure of the team did not change,

bringing us short of shared ownership h, although in practice decision-making was consensus-based.

Stage 4 -- Strengthening and amplifying dissemination and outreach.

Because of the collaborative, trusting relationships we had developed, in stage 4 stakeholders connected us to others in their networks. For example, after we met with the Men's Health Council, the chairman of the council, an alumnus of a national fraternity, connected us to the medical director of their three-state southern chapter leadership meeting. In another example, a local Medicaid care manager connected us with the state health department's Women's Health Branch, which resulted in a training for their staff and eventually membership in the Male Outreach Team of the state's "Be Smart" Medicaid Family Planning Program. Our relationship with the local family medicine clinic resulted in an article in the newsletter of the state's family medicine association. Post-presentation surveys indicated that audiences not only valued the information we were providing but considered themselves more likely to speak to patients or clients about marijuana use around reproduction as a result of meeting with us. Such evidence of interest allowed us to confidently move from local audiences to state and regional audiences.

We continued to modify messaging in response to audience feedback and created targeted materials to reach specific audiences -- lay audiences, patients, public health workers and healthcare practitioners – in specific contexts. For example, feedback from the fraternal organization's leadership conference led us to make subsequent presentations more interactive. Thinking through our materials in this iterative way was a source of insight when we began

developing issue briefs about maternal and paternal marijuana use to share with policy makers and institutional leaders nationwide -- the stage we were at as of this writing.

Active engagement with multiple audiences has had its challenges. It required that a number of presentation formats be kept updated. Issue briefs, once developed, could easily be shared with a wide audience, but will require modification as new information becomes available if they are to continue to be relevant. One solution to the problem of limited time was development of a recorded webinar on our subject matter. Originally the result of a request from a public health educator at the Men's Health Council meeting, the recorded webinar is something conveniently deployed when appropriate, although it does not provide the active engagement of an in-person presentation

Stage 5: Deepening partnership. As our work has matured, we sought opportunities to build on and deepen our relationships. This paper is itself an example of our ongoing collaboration with the coordinator of the Men's Health Council, who is an author. The CIPHERS team has written new grant proposals, and for those, we have sought the support and engagement of a number of the stakeholders mentioned in this case study and newly identified stakeholders. One result, based on the input of the Men's Health Council coordinator was the inclusion in a grant proposal of paid lay health educators from our local community, a form of community participation (Table 2). While the proposal was unsuccessful, we expect to use this idea in future projects. We recognize that deepening partnership of all types will strengthen outreach and dissemination.

Conclusion

Our experience translating CIPHERS research into clinical and public health practice represents an effective alternative to the dominant linear approach to research translation. The success of

our dissemination efforts was rooted initially in community engagement and progressed to partnership via a staged approach that reflected the insights of diffusion of innovation theory. Specifically, our approach emphasized adapting to community context and the utilization of early adopters to help improve and broaden outreach.

Identifying and engaging with early adopters allowed us to modify our strategy and build trusting long-term partnerships and networks. This enabled us to reach new groups in ways that we could not have originally anticipated. Feedback from early adopters and survey responses from early presentation audiences allowed us to include our target audiences' topics of interest, such as maternal marijuana use. Adapting to community contexts in this way helped capture the interest of a broader range of stakeholders. Additionally, including information on maternal marijuana use helped us craft a more comprehensive educational picture that incorporates how partners' marijuana use can affect one another. Thus, audiences received the content they desired, our content reached a broader audience, and we strengthened our teaching materials and methods. Moreover, bringing diverse perspectives inside our team allowed us to better reach a variety of audiences.

While our approach was effective, we did have some challenges related to the time-intensive nature of our approach. While tailored in-person presentations gained us valuable partners, the time it took to create and deliver individualized presentations limited the number of people we could reach. The organic nature of our engagement prevented us from being tied to an unsuccessful model, but it also took time to evolve.

Given the time intensive nature of catering to different audiences, we had to make challenging decisions regarding these efforts. Our initial decision to target clinicians and public health

professionals created the potential for more widespread impact, as each such individual could reach many others. However, the decision to not initially engage the affected community – young men of childbearing age and their partners – caused us to lose peer-to-peer knowledge transmission as well as their insights into what messages would best speak to them. These are aims of the paid lay health educator model we hope will be incorporated in the future.

In moving out to a broader community, the team will need to demonstrate appropriate understanding of and sensitivity to the perspectives of a variety of stakeholders. A particular concern is the possibility that research on epigenetic changes that may be associated with changes in neurodevelopment or behavior has the potential to elicit unwarranted feelings of blame or stigmatization among individuals with neurodevelopmental differences and their parents. We are confident that careful and authentic community engagement and messaging is the best approach to understanding and addressing the perspectives of such stakeholders while still making sure that people considering having children have all the information they want to have about reproductive choices. In sum, this case study illustrates choices that need to be made in carrying out a community-engaged, partnered, and non-linear approach to research translation aimed at improving public health. It also reflects and demonstrates the benefits of that approach, including its potential to address new needs and concerns as research evolves.

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Table 1: CIPHERS Approach to Outreach and Dissemination

Element	Source/Rationale	Examples
Staged dissemination beginning with early adopters	<p>Diffusion of Innovation Theory (DOI) – Diffusion begins with early adopters</p> <p>Philosophy and Practices of Community Engagement (CE) – Relationships are critical to success</p>	Initial contacts were with clinicians/public health practitioners with clear stake in issue and prior relationship with team members
Iterative active engagement with target audiences	<p>DOI – Effective DOI requires understanding social context</p> <p>CE – Effective practice requires sustained engagement for co-learning about needs, assets, priorities</p>	Ongoing engagement with key stakeholders allowed us to learn their needs (e.g., for information on maternal use) and identify new opportunities for dissemination over time
Multiple and tailored messaging	<p>DOI – DOI must be sensitive to context</p> <p>CE – Effective practice requires adaptation to context</p>	Materials and presentations crafted differently for lay and health professional audiences

<p>Amplification of dissemination through evolving networks</p>	<p>DOI – Diffusion progresses from early adopters to later-stage adopters</p> <p>CE – Change happens at the speed of relationships, trust, network development</p>	<p>Early adopter at local public health department led us to state health department and three-state lay audience</p>
<p>Contextualization of study findings</p>	<p>DOI – Recognition of diffusion as a process that requires time and has multiple inputs</p> <p>CE – Importance of being trustworthy in relationships</p>	<p>Contextualized study within larger bodies of research on paternal and maternal cannabis use, influence of environmental exposure on sperm epigenetics; were clear about early stage of research.</p>
<p>Emergent strategy</p>	<p>DOI – Diffusion happens over time and must be context-specific</p> <p>CE – Co-learning of collaborators and relationship-building happens over time, work adapts to context</p>	<p>Materials and presentations modified in response to audience feedback, new context; new opportunities developed as a result of growing relationships and networks</p>

Table 2. Involvement in Research Translation by Community Type and Stage

Translation* Involvement	No community involvement	Community informed	Community consultation	Community participation	Community initiated	Community based participatory	Community driven/led
Brief Definition	Community not included	Information gleaned from community, used to inform	Community provides input and feedback	Community has active, defined role	Work responds to specific needs, asks of community	Equal decision-making and ownership	Community leads and owns
Stage 1: Laying the Groundwork	<u>Clinicians, public health officials, affected community</u>						
Stage 2: Initial Community Engagement		<u>Clinicians, public health officials, affected community:</u> Dissemination of study findings is followed up by evaluation, with results used to shape further dissemination	<u>Clinicians:</u> Begins as consultations with clinicians to disseminate findings on cannabis and paternal reproductive health; results in team responding to clinician-initiated asks for help disseminating evidence on maternal reproductive health. <u>Public health officials, affected community:</u> Begins as consultation with public health officials; results in responses to specific requests for information on study findings initiated by public health officials and community organizations				
Stage 3: From Engagement to Partnership				<u>Clinician:</u> Clinician joins outreach team as paid member, and medical student as intern (leadership not shared)			
Stage 4: Amplifying Outreach and Dissemination							
Stage 5: Deepening Partnership				<u>Public health officials, affected community:</u> Public health official initiates role for paid lay health educators as participants in (unsuccessful) grant proposal. Public health official partners with team (including clinical members) on article.			

*Involvement continuum is based on the community engagement in research continuum developed by Key et al.¹⁸ In the context of this article, it refers only to the activity of translating or disseminating research findings.