



2017

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Michelle Levy

*University of Kansas, mlevy@ku.edu*

Cheryl Holmes

*University of Kansas, holmes70@ku.edu*


Amy Mendenhall

*University of Kansas, amendenhall@ku.edu*

Whitney Grube

*University of Kansas, whitney1@ku.edu*

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## Recommended Citation

Levy, Michelle; Holmes, Cheryl; Mendenhall, Amy; and Grube, Whitney (2017) "Engaging rural residents in patient-centered health care research," *Patient Experience Journal*: Vol. 4 : Iss. 1 , Article 6.

Available at: <https://pxjournal.org/journal/vol4/iss1/6>

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## **Cover Page Footnote**

**Acknowledgements:** The authors wish to thank the local and national partners involved in this project. These results would not be possible without their engagement. **Source of Funding:** This initiative was supported through the Patient Centered Outcomes Research Institute (PCORI), Washington, DC, USA. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the funder.

## Engaging rural residents in patient-centered health care research

Michelle Levy, *University of Kansas, mlevy@ku.edu*

Cheryl Holmes, *University of Kansas, holmes70@ku.edu*

Amy Mendenhall, *University of Kansas, amendenhall@ku.edu*

Whitney Grube, *University of Kansas, whitney1@ku.edu*

### Abstract

Patient engagement is increasingly recognized as a critical component in improving health care. Yet, there remains a gap in our understanding of the intricacies of rural patient engagement in health-related research. This article describes the process of engaging rural patients, caregivers and broader stakeholders to actively participate in an exploratory effort to understand rural perspectives around the patient-centered medical home model. Highlights of the project's engagement activities demonstrate how giving voice to rural residents can have a significant impact. Lessons learned point to the importance of six factors for successful engagement of rural residents as partners in health care research: building relationships, defining expectations, establishing communication guidelines, developing shared understanding, facilitating dialogue, and valuing contributions.

### Keywords

Patient engagement, patient experience, rural healthcare research

### Note

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### Introduction

Patient engagement is increasingly recognized as a critical component in improving health care and outcomes both in the United States and other countries. Broadly defined, patient engagement focuses on promoting active patient involvement and influence in health and healthcare.<sup>1</sup> It occurs at various levels from patient involvement in their own medical care (often referred to as patient activation) to participation in policy making and health systems improvement. The patient engagement described in this paper is comprised of rural resident involvement in an exploratory health care research initiative. Similar to a community-based participatory approach, this initiative was designed to involve rural residents as meaningful partners throughout the research process. Despite recent systemic reviews on patient engagement,<sup>2-4</sup> there is a gap in our understanding of the intricacies of rural patient engagement in health-related research. As such, the purpose of this paper is to describe how researchers engaged rural patients in one project so that others might benefit from the lessons learned by these authors.

### Engaging Patients in Research

Patient-engaged research implies a level of involvement that extends beyond the role of research subject. In the ideal, patients are equal partners with researchers in shaping and conducting research rather than having research done for, at, or to them. This shift has been fueled in the United States in part with the passage of the Patient Protection and Affordable Care Act of 2010 which created the Patient-Centered Outcomes Research Institute (PCORI). In funding efforts to help people make informed healthcare decisions, PCORI explicitly supports research that is guided by patients, caregivers, and the broader healthcare community. The push for patient involvement is also supported by research that suggests while patients' and practitioners' views may be similar, they are not identical in all aspects of care.<sup>5</sup> Some studies have found, for example, that patients place higher priority than healthcare providers on availability, accessibility, and time for communication.<sup>6-7</sup> In a recent study where patients and their physicians both rated the patient-centeredness of the care, patients' ratings of the care correlated to better treatment outcomes while physician ratings of the same care did not predict positive results.<sup>8</sup>

Patient engagement in research has been linked to enhanced quality as well as greater applicability and use of results.<sup>2-3,9</sup> Patient representatives can contribute across various stages of research in multiple ways. Specifically, patients, practitioners, and researchers may work together to develop relevant research questions; create user-friendly surveys or interview processes; and design suitable recruitment strategies to name just a few.<sup>2</sup> In particular, patients increase the relevance of study results for key stakeholders by identifying critical contextual factors and sharing translation and interpretation insights that reflect their lived experience.<sup>10</sup> Researchers note that involving patients is especially helpful in conducting research with 'hard-to-reach' populations.<sup>9</sup>

Despite movement toward greater engagement, Carman et al. notes that it is "still rare for patients to have more than a token amount of power and influence."<sup>11(p226)</sup> This absence of patient input into the development and dissemination of health care research may contribute to a lack of available, pertinent information for patients and providers trying to make informed health decisions.<sup>12</sup>

Patient engagement may be particularly critical for research related to rural health care. Individuals living in rural areas are more likely to be elderly, experience poverty and greater rates of chronic disease, and are more likely to engage in poor health behaviors compared to individuals living in urban areas.<sup>13</sup> Research suggests that rural individuals may have a distinct view of health that differs from their urban peers.<sup>14</sup>

The challenges that rural residents experience in seeking healthcare underscore the need for their input on the relevance of research questions and interpretation of data. Rural residents often face multiple barriers to accessing quality health care due to lower levels of insurance coverage, transportation challenges, and financial constraints.<sup>15</sup> As an area becomes less populated, the number of physicians decrease which is especially true for specialty providers.<sup>13</sup> Furthermore, social isolation, stigma, and concerns about confidentiality may be heightened in less densely populated areas.<sup>16</sup> Due to this structural and cultural uniqueness, research in health that overlooks the rural stakeholder perspective will likely result in findings that fail to fit in rural communities.

### **What Do We Know About What Works with Patient Engagement?**

Research points us to a developing body of knowledge about what works (or sometimes doesn't work) regarding patient engagement. While there are no comparative analytic studies to support a particular method of engagement,<sup>3</sup> there are promising strategies as well as cautions that are suggested in the literature. A recent systemic review found four essential components to

engagement: patient initiation, building reciprocal relationships, co-learning, and re-assessment and feedback.<sup>4</sup> Similarly, respectful working relationships and clear expectations are two oft-mentioned strategies. Clearly, effective interpersonal communication is a critical component of engagement. Specifically, spending adequate time to build relationships between patients and researchers is noted as important.<sup>4</sup> In contrast, a lack of understanding about goals of a research endeavor, purpose of patient involvement, and responsibilities of participants and organizers are major barriers to engaging patients.<sup>17</sup>

### **What about Rural Patient Engagement?**

Due to the unique realities of rural life, engaging with patients from rural communities might require some specific engagement strategies that differ from a typical approach. Distance and transportation challenges that arise in accessing health care can present logistical difficulties with engaging rural patients in research planning, implementation, and interpretation. Rural residents are likely to not have access to public transportation. Commutes may be longer in rural areas which may impact the amount of time that a person has to contribute to research related activities. In remote locations, internet access might be limited which reduces the number of means by which researchers can communicate with local stakeholders.

Engagement of rural residents requires particular attention to respect, discretion and confidentiality.<sup>18</sup> In rural communities, individuals are often interconnected in multiple personal and professional ways. The importance of these relationships and their continuity may heighten sensitivity to information sharing. Lower levels of education and higher levels of poverty in a number of rural communities could also be potential challenges to truly representative and meaningful patient involvement. For some rural residents, historic resource shortages and feelings of disconnectedness as well as a tradition of self-reliance or self-sufficiency may contribute to suspicions or mistrust of researchers and others seeking to engage.<sup>18, 19</sup> Divisions related to race and class that are often present in small communities could also impact interpersonal interactions related to engagement of rural patients.<sup>19</sup> Like engaging with any underserved or minority population, partnering with rural residents requires a high level of "cultural" competence.

### **Project Overview**

This paper describes an initiative focused on engaging rural residents and healthcare professionals to jointly build knowledge about patient-centered care and the Patient Centered Medical Home (PCMH) model. The PCMH model is part of a growing movement to transform primary care that holds promise for improving access and

health outcomes. However, the current PCMH model is largely physician-driven and may not address some patient priorities.<sup>20-21</sup> While the PCMH model is receiving a lot of attention nationally, the importance of aspects of the model to rural patients has not been widely studied. The authors of this article received a Eugene Washington Engagement Award from PCORI to fund this initiative. As part of a larger project, a local steering committee was formed to engage patients, caregivers, health care professionals, and other stakeholders to partner with researchers in implementing this work.

## Our Rural Patients and Stakeholders

A 17-member local steering committee included seven patients/caregivers (referred to hereafter as patients or rural residents) along with seven professionals from Federally Qualified Health Centers (including a physician and administrator), community outreach agencies, and a healthcare foundation as well as three university researchers. Local stakeholders represented two rural counties from contiguous Midwestern states. Counties were selected to participate based on existing relationships between the researchers and local health care professionals. While the counties varied in total population by around 20,000, the largest cities in each of the counties were around the same size (approximately 4,500-5,550 residents).

Recruitment of rural residents occurred with the assistance of a community outreach agency from each rural county. Agency representatives, provided with a description of the project and expectations for committee members, were asked to identify local rural residents who were not also providers or representing other organizations. The rural patient and caregiver representatives reflected diversity in age, gender, race/ethnicity, and socio-economic status to achieve a balance of stakeholder perspectives.

## Patient and Stakeholder Involvement

The local steering committee met five times over the course of the year-long project. The two counties involved in the initiative are approximately two and a half hours in distance from each other. Researchers initially suggested that the committee meetings rotate between the local communities but the rural resident representatives preferred to meet in a central location, a major metropolitan area that is a 1-1 ½ hour drive from each county. In addition to the joint meetings, a researcher visited each local county on three occasions between meetings to share and collect additional information.

Patient and other stakeholder involvement included refining the project focus and contributing to survey development and distribution, data interpretation, and dissemination of project results. Specifically, two surveys

were developed to collect rural perspectives, one for rural residents and one for professionals. The local steering committee reacted to draft questions and suggested numerous changes including addition and deletion of questions, different wording for instructions and questions, modifications to format, and input on overall length. Committee members also shared ideas on where to distribute the survey. After the survey was administered, preliminary aggregated results were shared with the committee, and they provided initial interpretation and suggestions for additional analysis. Results of the survey are discussed in detail in another manuscript.

## Engagement Efforts

Recognizing that meaningful patient engagement is not always easy, the local steering committee was structured to facilitate rural resident participation. Specific, purposeful activities to engage patients and other stakeholders addressed six areas: building relationships, defining expectations, establishing communication guidelines, developing shared understanding, facilitating dialogue, and valuing contributions.

### *Building relationships*

Building genuine relationships is an important first step of group formation. Ample time was set aside in initial meetings for getting to know one another on a personal level. An icebreaker that focused on each member sharing a story about his/her name or nickname facilitated introductions and offered initial openings to learning about each other's families, culture, hobbies or interests. While typical meeting introductions focus on sharing job titles and credentials thereby immediately differentiating between professionals and patients, this approach allowed group members to begin by connecting as individuals with equal and unique experiences to share. After the initial meeting, a directory was created to allow members to share their contact information and personal bios, as desired. In addition, relationship development was aided through breaks and refreshments, such as offering food and drinks when members arrived knowing some had been traveling nearly 2 hours and then having lunch together with a true break to allow informal visiting.

An explicit part of the project design that facilitated relationship building included the staff of the local outreach organizations who served on the committee. These individuals made themselves available to the committee members from their counties, providing the residents with someone local that they likely knew and could talk to about questions and concerns while the relationships with researchers and other committee members were being developed. These local contacts also helped to organize transportation to the meetings when needed.

### ***Defining expectations***

All stakeholders need to understand the goals of the research endeavor as well as the purpose of their involvement and their proposed role and responsibilities. Prior to the first meeting, committee members received an overview of the project to begin to familiarize themselves with the work. This overview included a description of the process, expectations for members (such as attendance at each meeting and reading handouts between meetings), and the desired outcomes and deliverables for the project. Each meeting started with a review of roles, expectations and processes for involvement. In addition, members were regularly reminded that offering their perspectives as rural health care users was central to the initiative. The project team decided to call the patient/caregiver representatives, “rural residents” rather than “patients” as not all participants identified themselves as patients. Though some of the organizational structure and project design was pre-determined by the initiative’s funded proposal, rural residents were encouraged to provide guidance and lead decision-making whenever possible. For example, as previously described, meetings were held at a time and place decided on by the committee and driven by preferences of the rural residents.

### ***Establishing communication guidelines***

Effective interpersonal communication is a foundation for relationship building and engagement. To create a safe environment for direct and open communication, steering committee members spent time in an initial meeting contributing to the development of a set of group guidelines for working together. For rural residents who continue to live together in the same small communities, a shared understanding by the group of the importance of maintaining confidentiality was important. These guidelines were reviewed at the beginning of each meeting to build trust and a sense of community. In addition, researchers adopted strategies to reinforce the guidelines. For example, to support the guideline that “there are no dumb questions”, researchers specifically solicited questions throughout the meetings, and members were encouraged to write down questions and comments that they might not feel comfortable sharing with the larger group. At the end of each meeting, members completed a short survey asking for suggestions on how future meetings could be improved or if there were any areas in which they would like additional information or clarification. Following each meeting, researchers sent minutes by U.S. postal service to all rural residents as some did not have an email address and for others, the internet connection was not always reliable.

### ***Developing shared understanding***

From the beginning, patient and professional stakeholders learned about PCMH together. There were no assumptions made about what may or may not have been known by different group members. Researchers

presented basic information about PCMH to the local steering committee so that all members were working together with common definitions and general understanding. Rather than using a traditional literature review to inform the group about PCMH research to date, a stakeholder guide was created that summarized what PCMH is, how it has been used in rural areas, and what we know about how it works. The guide was intentionally designed to function as an engagement tool in that it was written in a short, easy-to-read format and presented real-life examples to help the reader understand how PCMH works in everyday practice (see <http://bit.ly/1GPuDkk>). A literacy check was done to ensure that the guide could be understood by readers of various education levels and it also included a list of acronyms commonly used by health professionals.

Knowing that not everyone learns in the same way, a subject expert on PCMH was brought in to verbally present to the committee some of the same information shared in the written guide which also allowed an opportunity for additional questions to be addressed. The group members’ level of understanding was verified in several ways including questions asked over the course of the project. Members were asked to rate how much they feel they know about PCMH using a 5-point scale, with 1 = I don’t know anything about PCMH to 5 = I know a lot about PCMH. Over the course of the initiative, there was an increase in members’ reported knowledge of PCMH with a mean score of 3.0 (SD=1.18) at the beginning of the project and a mean score of 3.9 (SD=.79) at the end but the small sample size and missing data restricted our ability to determine if this was a statistically significant difference.

Throughout this process, opportunities were provided to encourage participants to share their thoughts and reactions about the realities of PCMH in rural areas. The residents, representing two counties from different states, noted with surprise how some of their shared experiences of rural health care had both stark similarities and differences. They also noted that prior to participating in this group, there were times that they felt that the challenges they experienced in accessing health care were unique to themselves and perhaps were due to their income level or race. Hearing that other rural residents in another state had had similar experiences appeared to create a feeling that they were not alone along with a corresponding sense of empowerment. The professionals expressed on multiple occasions the value of hearing first hand from the rural residents and how that information truly aided in the understanding of how medical care is experienced by the end user.

### ***Facilitating dialogue***

The discourse between patients, stakeholders, and researchers revealed insights that contributed to new

understanding and knowledge development. Several strategies were utilized to facilitate the sharing of experiences and ideas. For example, after listening to highlights of the project's survey findings, group members were encouraged to write down something that surprised them about what they heard, a finding that should be shared, and a question to consider during additional analysis. This information was shared with the full group to generate conversation about each of these topics. To ensure that all voices were heard, each stakeholder was asked to relate an experience with patient-centered care, sharing as much or little (or none) as they felt comfortable doing. Each member was paired with another who took the lead in identifying patient-centered aspects (negative or positive) in the narrative shared. After the sharing, the personal stories and comments were collectively reviewed to identify broader themes related to patient-centered care. At another meeting, members' nameplates were used to "assign" seating to encourage interaction between a mix of perspectives. Having a meaningful number of rural residents (as opposed to a token 1 or 2), allowed the group to recognize commonalities or differences by building on one another's stories thus contributing a richness and depth to the conversation. Finally, many of the committee's professionals were or had been rural residents and could draw on that lived experience to offer understanding in multiple ways on how rural lifestyles and realities impact health.

### ***Valuing contributions***

As the rural stakeholders were central to the success of this research initiative, it was important to show the patients and caregivers that their input was valued. This was done in several ways. The patient/caregiver representatives were paid as consultants for their travel and time. Sharing meals together, as is common in many rural communities, encouraged social interaction and showed appreciation for participants' time and involvement. Information shared by stakeholders was reflected to the participants in the form of meeting notes to show that feedback was heard. Information and ideas shared by stakeholders were used if at all possible, and positive feedback was passed along to stakeholders. For example, when the project funder acknowledged the initiative's efforts, this recognition was noted with all stakeholders along with acknowledgement of their role in this achievement.

### **What Impact Did Rural Residents Have?**

As noted by Brodt and colleagues,<sup>10</sup> patients bring a unique understanding of a disease or condition to the research endeavor. In the case of our stakeholders, this distinct perspective was not disease specific but focused on their common experiences as rural residents who are seeking and utilizing health care. While systemically measuring the impact of patient engagement was not a

formal part of the work, the process clearly had a meaningful impact on the research, the professionals involved in the process, and the rural residents themselves.

Patients and caregivers strengthened the research through their work with health care professionals and researchers on a local steering committee. Overall, rural residents contributed to refining the research questions, shaped the content and process of the surveys, and helped put the language into a rural context. Residents also shared suggestions for reaching underserved populations with the survey. All rural residents (patients and professionals) provided important context for translating finding into everyday practice, including ideas regarding the adoption of research evidence into practice settings.

Rural resident committee members' suggestions for the surveys were validated by the survey results. Some of the survey questions suggested by rural patients related to aspects of care that are not an explicit part of the PCMH model as currently defined. Rather than disregarding these ideas, researchers incorporated the questions into the survey to see if they might reveal new findings about rural residents' perspectives on patient-centered care. For example, rural committee members raised the issue of the importance of the receptionist in setting a patient-centered tone for a visit. On the survey question, "how I am greeted by the receptionist is very important to me," eighty-one (81%) of rural respondents agreed. For more information on the survey and other ways in which rural residents' suggestions yielded new findings about patient-centered care, see Holmes et al.<sup>22</sup>

Hearing directly from rural residents about barriers and facilitators to health seeking and care seemed to resonate with professionals in a meaningful way. Practitioners listened respectfully to patients and caregivers talk about their encounters with health care systems and asked questions about their preferences for interacting with health care professionals. Professionals noted that much of the information they see about PCMH focuses on what providers need but being engaged with patients helped them to better understand health care delivery from the patients' perspectives.

Finally, patients and caregivers reported they felt that their voices were heard and contributions valued as reflected in the comments below.

- "We were listened to. This is how you feel valued."
- "We weren't spoon-fed what to think. Information was put out there and then we were asked 'what do you think?'"
- "First time I saw the survey [developed by the local steering committee], it was a feeling of pride. We could see our parts in it. It felt like we accomplished something."

- “It was worth our time and effort but we want to see the results used. That will really make it worth the time.”

Another impact noted was that rural residents were empowered to become more active in their own health, and that of their fellow community members. For example, one resident reported trying the strategy of keeping a notebook of health information as mentioned by another member at a previous meeting. At the group’s last meeting, the residents expressed interest in exploring options for how the work might continue, particularly, in how they could educate their neighbors about the project and what they can expect from patient-centered care. As a result, the committee created a brochure so that project information could be disseminated locally.

### Challenges and Limitations

Overall, the process described in this paper achieved meaningful patient engagement. All rural residents attended every meeting (including one who became a new mother midway through the process) and all actively participated in different ways. Notably, residents, professionals and researchers alike expressed an interest in continuing the work after the project came to an end. Despite this success, there were challenges and limitations that point toward areas of future research.

Engagement includes sharing one’s perspective within a group which requires some level of risk taking. As with any group, there were times in which more vocal members of the committee overshadowed others. On occasion, a few of the rural residents seemed reluctant to contribute their thoughts. It is difficult to determine if this was due to the topic being discussed, an individual’s level of introversion, familiarity with participating in a committee process, current or previous connections between residents, or the presence of professionals from their local community. It is important to acknowledge there are inherent power differences between professionals and residents. While these differences did not seem to outwardly manifest themselves during the meetings, there may have been underlying tensions that impacted interactions and communications.

Engagement takes time and this may not always correspond to the timelines of researchers, funding, and diverse participants. For this project, momentum was still building as the project’s funding was coming to the end. While the group offered important new details about health seeking by rural residents, there were potentially sensitive topics that did not come to light. While we purposely selected a diverse group of residents that represented racial and socioeconomic diversity, the impact of discrimination, poverty, and other issues that create potential disadvantage went unshared or unspoken. It is

interesting to consider if more time might have deepened the level of engagement thereby enabling more in-depth discussion and sharing of additional layers of information.

Likewise, there were no real conflicts or disagreements among the group during the engagement process. This could have been due to the nature of the work as this initiative was focused on information gathering rather than attempting to establish consensus or agree on a course of action. Again, it is interesting to consider if this dynamic might have been different given more time or in-depth information exchange. While the committee reflected together on their engagement at the initiative’s end, including a separate meeting with one of the researchers and the rural residents in their home counties, individual de-briefing around the interpersonal aspects and group dynamics might reveal new insights related to engaging rural residents.

Finally, one might also consider how the process might have differed with urban residents or through utilizing other engagement strategies. As an example, one of the last meetings of the steering committee was cancelled due to winter weather. Using technology might have allowed this meeting to continue but may have changed the dynamics of the engagement process in new ways. Also, there may have been differences if the residents had chosen to hold meetings in the local communities as opposed to convening in a central location or if residents were provided with greater leadership responsibilities such as co-facilitating the meetings.

### Conclusion

A majority (59%) of rural residents who responded to the patient survey that was part of this research initiative indicated that it is very important that their health care person “really understands” rural life.<sup>22</sup> We would argue that it is equally important that health care researchers “really understand” rural life in order to design and implement research that truly contributes to improving the health of rural communities. A better understanding of rural health attitudes and beliefs is needed.<sup>14</sup> Meaningful engagement in research is a way to facilitate this understanding. Too often, when patients are involved in providing feedback it is in a limited manner such as through satisfaction surveys or feedback boxes. In order to develop research-informed health care models and systems that are truly patient-centered, patients need to be involved in meaningful ways throughout the process.

In many ways, engaging rural patients in improving health care is no different than engaging any individuals in this process. This initiative confirmed key factors to engagement to be building relationships, defining expectations, establishing communication guidelines, developing shared understanding, facilitating dialogue, and



valuing contributions. These keys parallel those noted by other researchers, namely, patient initiation, relationship building, co-learning, and reassessment and feedback.<sup>4</sup> Within these broad key factors, however, there were ways that engagement efforts needed to be tweaked to meet the unique preferences and values of rural residents. However, this particular group of residents may differ from other rural residents so these insights may not be generalizable to working with all rural patients. In fact, we would suggest that other researchers use these results merely as a starting place for discussions with rural patients involved in their work.

The lessons learned in engaging rural residents to participate in health research are applicable to the parallel process of activation or engaging patients more fully in their own health care and wellness. For example, in sharing information with the local committee, it was important to remember that not all patient representatives had computer or email access, or even if they did, some preferred to receive hard copies of information as well as electronic. Allowing patients to choose the way that works best also applies for patients receiving information from their physicians.

There is value in including rural patient perspectives as health care research is designed and findings are interpreted and put into practice. Through purposeful engagement efforts, this project brought patients and caregivers together with professionals who are delivering and funding services to inform patient-centered research efforts. Engaging patients in improving health care and health care-related research is gaining momentum through initiatives such as the PCORI that puts funding behind research that is patient driven as well as through PCMH recognition which requires patient involvement in primary care quality improvement. Our experience may be useful for others seeking to strengthen the rural voice in health care research and improvement efforts.

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