
Research Methods

Developing a patient and family research advisory panel to include people with significant disease, multimorbidity and advanced age

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Abstract

Background. People who have experienced illness due to significant disease, multimorbidity and/or advanced age are high utilizers of the health care system. Yet this population has had little formal opportunity to participate in guiding the health care research agenda, and few mechanisms exist for researchers to engage this population in an efficient way.

Objective. We describe the process of developing a standing patient and family advisory panel to incorporate this population's voice into research in the USA.

Methods. The panel was created at the University of Colorado. Preliminary panel development consisted of a needs assessment, information gathering and participant recruitment. We collected feedback from researchers who consulted with the panel and from panel members in order to better understand the experience from the patient and family member perspective.

Results. The patient and family research advisory panel consists of eight advisors who have experience with significant disease, multimorbidity and/or advanced age, two physicians and a program manager. The panel meets every other month for 2 hours with the main purpose of advising diverse researchers on health care studies.

Conclusion. People with significant disease, multimorbidity and/or advanced age represent a growing demographic in the USA, and their engagement in research is essential as the model of health care delivery moves from volume to value.

Key words: Advisory committees, comorbidity, delivery of health care, patient participation, program development, underserved populations.

Introduction

Historically, people who have experienced significant disease, multimorbidity and/or advanced age have been excluded from research because they are either considered to be too ill or the research is too narrowly focused on a single disease state (1–7). These patients face complicated medical decisions and are high utilizers of the health care system (8). Increasing the value of health care for this growing demographic is vital to the US health care system as the model of delivery moves from volume to value (9,10). However, this population has had little formal opportunity to participate in guiding the health care research agenda, and few mechanisms exist for researchers to engage this population in an efficient way.

We set out to establish an advisory panel comprising patients with significant disease, multimorbidity and/or advanced age that would contribute to shared research agendas with diverse researchers at the University of Colorado. In this article, we focus on the methods used to develop this panel, including chief challenges and successes.

Methods

Context

Members of the development team were two physicians with expertise in shared decision-making and a research assistant with a social work background. Preliminary development consisted of three processes: a needs assessment, information gathering and participant recruitment. We also collected feedback from panel members and researchers who consulted with the group.

Needs assessment

We conducted a local needs assessment to learn how University of Colorado researchers envisioned engaging patients with significant disease, multimorbidity and/or advanced age in the research process. We focused broadly on three dimensions, identified by common shared decision-making consultation requests: a research advisory group, shared decision-making tools and measurement of decision-making and engagement outcomes. This online survey was distributed to all researchers with a known interest in engaging patients in research yet without clear mechanisms for doing so.

Information gathering

Concurrently, we conducted a review of literature and online resources to identify best practices related to patient engagement in health research. The results informed our panel development strategy, including discussions about the appropriate type and degree of patient engagement (11–13). We also consulted with leaders of existing patient advisory councils at both the University of Colorado and other institutions, attended patient advisory council meetings and participated in patient engagement webinars.

Recruitment

Significant disease, multimorbidity and/or advanced age served as informal guides to identifying high utilizers of health care resources. Our primary recruitment strategy was through existing relationships. We received recommendations of patients to contact from colleagues at University of Colorado Health's University Medicine Denver practice. Other methods included recommendations from the University of Colorado Hospital's Director of Patient and Family Centered Care (PFCC) and patient participation in a study whose inclusion criteria included multimorbidity and advanced age.

We developed a brief description of our vision for the panel and an interview guide for use during recruitment phone calls (Box 1). Guide development was highly iterative, and changes were made based on development team discussions during the recruitment phase. The guide was designed to introduce the concept of the research advisory panel, learn about candidates' experience with

Box 1. Phone call guide used by program manager when making initial contact with prospective advisors for the patient and family research advisory panel at the University of Colorado

Caller introduction
Brief description of panel idea
Key points

- A new patient research advisory program through University of Colorado.
- The goal is to help doctors better focus their research to align with patient preferences and needs: 'We want to know whether the research that doctors think is helpful is actually helping people'.
- Current stage is contacting people to determine where they might fit best as within this program, i.e. database of patients available for consultation on specific research projects or standing patient and caregiver research advisory panel.

Does this sound like something you might be interested in?
Do you have any questions for me?
If you are interested in getting in involved, would you be willing to answer some questions that will help me get to know you better?

Questions

- (1) Would you be willing to tell me a little about your experience with the University of Colorado health care system? If you feel comfortable sharing, you could also tell me about the health concerns you have. ('Major medical events, conditions, medications, etc.')
- (2) Do you have experience with any patient advocacy groups? If so, please tell me about it.
- (3) Do you have experience with research of any kind? ('Prior research experience is not necessary.')
- (4) If we develop an ongoing research advisory panel, do you have any special interests or experiences—based on your interaction with the health care system or general life experience—that you would contribute to the group?
- (5) Would you be willing to complete a small amount of research training to equip you as an advisor?
- (6) What kind of commitment would you be willing to make as a participant in this program? Available as needed? Able to attend recurring meetings? ('At most, this would be once/month.')
- (7) What would be the best time and day for you to meet?
- (8) Is there anything else you would like us to know about you?

Those are all the question I have for you. Do you have any questions for me?

Our first step is to gather those interested for an initial meeting. I will plan to contact you again within the next month or so. In the meantime, you can call me if you have any questions.

illness, gauge interest in helping to steer the nascent program and identify individuals who are authentic and empowered rather than advocates in order to avoid conflict of interest (11,14). An ability and willingness to move beyond personal experience and understand shared, nuanced and/or competing agendas was a key qualification. During the recruitment phase, we created an advisor role description (online Supplementary Material 1) to summarize expected responsibilities.

Advisor and researcher feedback

Members of the advisory panel are encouraged to share their concerns and ideas with the program manager on an ongoing basis. Ten months after the first meeting, we contacted founding group members to request formal feedback on their experience. Advisors were invited to answer the following questions: (i) What has your experience as a research advisor been like so far? (ii) Do you feel like you have been able to have an impact? What could you do to have more of an impact on the research? and (iii) What do you like about the current process and what would you like to see changed? Approximately one month after meeting with the panel, researchers are invited to share how they incorporated the advisors' feedback into their research project. In addition, researchers are encouraged to return to the group to reengage with the panel as their projects progress.

The Colorado Multiple Institutional Review Board does not deem advisory councils to be under their purview, and as such, this is not human subjects research. We present our findings with the hopes that methodological lessons learned may be helpful to others seeking to engage people with significant disease, multimorbidity and/or advanced age in an advisory capacity.

Results

The needs assessment survey was sent to 83 researchers and completed by 50 researchers. Respondents represented a range of departments, from emergency medicine to community and behavioural health. Sixty-eight percent of respondents said that feedback from an advisory panel would be useful, citing areas such as research questions, patient recruitment, outcomes, patient-centred outcomes and future grants (Table 1).

Given our objective of initiating a mutually beneficial relationship between researchers and patient and caregiver stakeholders, our review of literature and resources was not limited to participatory research. We determined that stakeholders would serve primarily in an advisory capacity, i.e. using 'their knowledge to influence long-term, strategic decisions' and helping 'to define fundamental and clinical research questions' (11) while recognizing that patient

engagement exists along a continuum (15). In the process of meeting researchers through the advisory panel, we anticipated that opportunities would arise for advisors to also operate in research partner roles on study teams (11,13). The review revealed gaps, including how to effectively maintain a panel available to advise diverse researchers and how to engage people with significant disease, multimorbidity and/or advanced age. This is a community not defined by a shared geographic location or disease state, but rather by its broad albeit disenfranchised membership. Patient engagement efforts largely focus on a narrow disease state or demographic; our findings demanded a responsive agility to adapt to the needs of patients, caregivers and researchers. In order to accommodate the changing health needs of this population, we determined that an advisor approach is more appropriate than a partner approach.

The patient and family research advisory panel was created to connect patients and caregivers with University of Colorado researchers seeking input at any stage of research. Panel development was funded through an internal grant of 10 000 USD from the Dean of the School of Medicine at the University of Colorado designated for research infrastructure available as a campus-wide resource. The panel is under the auspices of the Shared Decision Making core in the Adult and Child Consortium for Health Outcomes Research and Delivery Science (ACCORDS) and affiliated with the Colorado Clinical and Translational Sciences Institute and the University of Colorado Hospital's PFCC. At present, the research advisory panel consists of eight advisors, two physicians and a program manager. After 1 year, the panel had retained five of its original advisors. In early 2016, three additional advisors joined.

The panel first convened in April 2015 on the University of Colorado's Anschutz Medical Campus with nine prospective advisors in attendance. The purpose of the initial meeting was to establish the group's vision, provide tangible examples of patient and caregiver contributions to research and establish expectations so participants could determine whether the group would be a good fit. It was emphasized that the advisors had a large part in determining the structure and direction of the panel. A second meeting date in June was agreed upon before the meeting concluded.

Panel format

The structure and function of the research advisory panel was discussed at the second meeting. Rather than have a fixed term length, the group decided that an informal annual review would ensure both the advisor and panel continue to benefit. For the first year, the panel met every other month for 1.5 hours, with additional communication occurring as needed between meetings. In June 2016, the panel decided to begin meeting for 2 hours with lunch provided. Advisors are expected to attend meetings regularly with the option of advising

Table 1. Results from the advisory panel portion of the online needs assessment survey sent to 83 researchers with a known interest in patient engagement at the University of Colorado

Question	Response	Number of respondents
Would it be useful to your research to have access to a patient–family advisory panel comprising people or family members of people with multimorbidity or with experience facing a major life-threatening medical decision?	Yes	34
	No	5
	Not sure	11
How might you use such a panel? ('excerpts')		
'To help with patient-centred research questions'		
'Advice on appropriate research design and practice'		
'To develop important resources to assist with improved decision-making in multi-disciplinary clinics'		
'An advisory board could advise me on the development and testing of interventions'		
'Help interpreting and communicating research'		

on an ad hoc basis between meetings when contacted via email with research engagement opportunities.

In October 2015, two external researchers who had expressed interest (via the needs assessment) presented to the panel. The panel decided that the presentation model should be flexible, i.e. one or two presenters per meeting depending on the project, in order to ensure enough time with each researcher. It was also decided that any study materials relevant to the presentation would be distributed in advance, allowing advisors to come prepared to share their feedback. Projects presented have ranged from the development stage to data collection (Table 2).

Key documents

Several documents were created to support operations of the research advisory panel. Group norms (Box 2) are the standards the group agrees to uphold. The advisor profile (online Supplementary Material 2) provides the program manager with contact information, personal preferences and a short summary of experience and interests. Finally, we created a researcher presentation request form (online Supplementary Material 3) modelled after community-based participatory research initiatives on campus, which researchers must complete if they wish to seek feedback from the panel.

The advisor experience

Of the four advisors who provided formal feedback regarding their experience on the panel, two described the experience as 'positive' and 'enlightening'. Several also identified learning about current research as a benefit: 'I have loved learning about the process involved with research projects from inception to final use in patients' lives and health care'. One advisor suggested that impact on research could be increased by finding 'meaningful ways to be more involved in the research proposal post-meeting'. Overall, the advisors were complimentary of how the group functions as a whole. One advisor commented: 'Our group is articulate and trusting...It is a privilege to be part of this group'. Another described the 'implicit contract' between guest researchers and advisors that hinges on 'members begin prepared and the ability to provide feedback without recrimination'. One advisor remarked, 'it's not important for us individually to have impact, but rather for the panel collectively to do so'.

The researcher experience

We received project updates from five researchers who have presented to the panel. All found consultation with the advisors helpful. A researcher developing a survey of lung cancer patients and their caregivers as well as a patient decision aid stated that she 'acted on almost

all of the suggestions, which were extremely constructive. This panel led to an improvement in clarity and readability of the survey and decision aid'. Another researcher developing a mobile intervention for caregiver support indicated that 'the group was very helpful in terms of providing useful feedback...to meet the needs of caregivers' and shared some of the specific ways that feedback was incorporated, such as 'language...from the participants was used verbatim in the program'.

Discussion

Our approach to panel development has resulted in a robust group that is mutually beneficial for patients, caregivers and researchers. This method embraces continual development through being reflexive and forward thinking.

Lessons learned

The nascent concept of connecting advisors to multiple researchers required a large degree of flexibility. Our desire to create a patient-driven group presented interesting challenges: How do we invite people to participate in a new group when we cannot say exactly what that group will look like and how it will function? How do we lay a foundation for a group whose structure and vision are meant to be determined collaboratively? We learned to let the panel evolve. Knowing how everything would unfold was not realistic, and transparency was key. Being forthcoming about the fact that we did not know how exactly this panel would look attracted those who could tolerate ambiguity and collaborative learning. We also emphasized that this type of patient engagement was not for everyone and that it was perfectly acceptable for those who expressed initial interest to decline to participate.

We pursued an advisory form of patient engagement based on the needs and interests of patients and caregivers as well as researchers. Advising multiple researchers is appealing to those who recognize the importance of research broadly and value the opportunity to contribute specifically to diverse local projects. We took as a guiding principle the belief that patient engagement 'is not a one-size-fits-all effort; customization is required' (16). For this population, the breadth of experience with illness makes it possible to advise adeptly on diverse projects rather than on a single study focused on one disease state. Serving in an advisory capacity recognizes the unique contributions that those with significant health care system usage can offer. Every effort was made to enact inclusion strategies, from creating name badges with first names and no titles to recognizing the advisors as the experts to ensuring that researchers refrain from using jargon (17).

Table 2. Research that the patient and family research advisory panel at the University of Colorado has engaged with as of August 2016

Topic	Stage of research
Clinician-patient interaction in primary care settings	Data collection
Colon cancer screening decision aid	Decision aid development
PIVOT centre	Proposal submission
Decision-making by patients with lung cancer	Ready to submit to the Institutional Review Board
Mobile intervention for improving depression, anxiety and intimacy in caregivers	Intervention development
Hospice decision aid	Early stage of project development
Improving methods for surveillance and prediction of the reach and adoption of FDA drug safety warnings	Proposal development
Surgical risk preoperative assessment system	Data collection
Helping caregivers participate in stress management by increasing awareness of physiologic stress	Proposal development

Box 2. Group norms guiding the patient and family research advisory panel at the University of Colorado

Group norms are the standards we have committed to uphold during our time together. These agreements allow us to create a safe place for everyone to participate.

- (1) Step up, step back. If you are normally quiet in a group, challenge yourself to speak up. If you normally talk a lot, challenge yourself to allow others to speak first.
- (2) Respect other opinions and experiences. Your advising is valuable because you contribute unique perspectives and unique ways of sharing this feedback. Be kind.
- (3) Maintain confidentiality. Advising often involves sharing a part of one's personal experience. It is very important that such information stays within this group.

One of the biggest challenges we encountered was clarifying how advising on clinical operations and advising on research differ. The patient's main interface with the health care system is clinical operations and there is often overlap between the two (18). Providing tangible examples of how other patients and caregivers have advised during the research process was helpful in defining this distinction. For example, in the first meeting, we showed a clip from a decision aid video about left ventricular assist devices that the ACCORDS Shared Decision Making core had recently created (19). Patients and caregivers were featured in the video, and afterwards, we described how the video was iterated based on patient and family feedback. Sharing examples of clinical operations as compared to research reinforced the distinction.

An ongoing part of our panel development is basic research training to ensure that we have a shared language around health care research. We have given two 20-minute presentations on funding in health care research and research methods. Based on feedback from the advisory panel, the presentation slides and narrative content were revised and then recorded for posting online. Education also occurs on an ongoing basis with every researcher presentation. We create an atmosphere where inquiry is encouraged and learning is embraced as part of the experience. While we drew from excellent material on training community members in research practice, none of the existing curricula were an exact fit (e.g. 20–23).

Sustainability

Establishing a plan for the sustainability of this panel is a priority. Because this panel is not supported with a specific grant-funded project, we are looking at ways to ensure its maintenance and growth into a campus-wide resource. As opposed to being tokenistic, a standing panel like this recognizes that patient and caregiver perspectives are valuable beyond a singular study (24). Furthermore, demonstrating the applicability of this panel broadly to the local research community is a requisite for future institutional support.

At present, we do not require guest researchers to contribute funding in order to meet with the group. While this is one possibility, we do not want to deter researchers who do not have funding available to contribute. The issue of funding also affects advisor compensation, which becomes more challenging when not built into a grant proposal budget. Advisors expressed that being able to contribute was sufficiently meaningful and compensation was not needed or expected. However, the Patient-Centered Outcomes Research Institute (PCORI) and others view compensation as an

essential component of recognizing the value of patient and caregiver contributions despite the lack of existing payment models (25). In August 2016, in accordance with emerging best practices, we discussed modestly compensating advisors. The group had mixed views on compensation and ultimately agreed that individual advisors could elect to receive or decline a gift card for each meeting. The program manager collected said preferences confidentially by email. Gift cards are mailed to advisors who have opted to receive compensation following each meeting. Advisors may change their compensation preference at any time. As this is a campus-wide resource, we expect that ongoing grant funding from the university will support this effort.

While we did not have a clear precedent for developing and maintaining a successful, engaged group, we came to view learning together as a necessary and important part of the process (26). Demonstrating a strong investment in the advisory panel members as individuals and as a collective, empowered group takes time yet is essential to the panel's sustainability (24). Relationship-building cannot be underestimated in this context, especially when every advisor has extensive experience with the health care system. A next step is how to connect interested advisors with researchers seeking a patient or caregiver research team member. Increased patient engagement—whether through joining a specific research team or through long-term membership on the panel—will require considering whether advisors can continue to contribute as 'typical' patients or caregivers. We are also determining how to measure success. We have anecdotal evidence from advisors and researchers that the advisory panel is mutually beneficial, but we will need to identify additional specific outcomes, such as operationalizing and normalizing a shared research agenda.

Conclusion

We were unable to locate any examples in the literature of standing patient panels involving people who have experienced significant disease, multimorbidity and/or advanced age. This article summarizes the preliminary efforts to develop a panel to engage a population often excluded from research. Our patient and family research advisory panel has begun to give such individuals a voice in research—both in contributing perspective to the broad research agenda and advising investigators about ongoing research. While this population does not fit the traditional definition of underserved, they are vulnerable in the context of health care research, and the need for enhancing research with this population is pressing.

Supplementary material

Supplementary data are available at *Family Practice* online.

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