

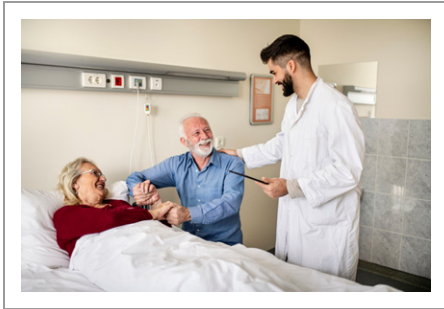
INNOVATIONS AND PROVOCATIONS

Patients as Researchers in Adult Critical Care Medicine Fantasy or Reality?

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To improve health and health care, we must forge an active partnership between healthcare professionals, patients, and family members (1). This includes having patients and family members as members of the research team. Engagement needs to go beyond the traditional confines of research *participation* to research *partnership*, whereby patients and family members (subsequently inclusively referred to as “patient researchers”) actively participate in the conduct of research in critical care medicine (beyond the traditional role of participation). We employ the Canadian Institutes of Health Research definition of “patients,” which “is overarching and is inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends” (2). We are all patients and family members at some point during our lives; the authors of this paper are the family member of a former intensive care unit (ICU) patient and patient researcher (B.G.S.), researchers in critical care

medicine with experience engaging family members (K.M.F. and H.T.S.), and an intensive care physician (H.T.S.). We discuss why researchers should engage patients in research, the practicalities of engaging patients as researchers, examples of engagement, and finally common pitfalls and mitigation strategies for patient engagement in research.

Why Engage?

Why should researchers and clinicians engage patients in critical care medicine research? Are we merely making changes to the status quo because some funding agencies and journals require the involvement of patients, or are we experiencing a meaningful shift in traditional roles? This is a thought-provoking question, because engagement is not the norm. Structural barriers exist that have traditionally barred patients from engagement outside conventional roles (i.e., as participants). Research is set up to benefit researchers, such that patients are a means to an end for academic advancement. Why has engagement been so challenging to date? Many challenges contribute to this: Do researchers/clinicians believe patients are ill equipped to undertake these roles? Is the power differential between researchers/clinicians and patients too large to overcome? Or is it that researchers/clinicians don't know how to engage patients in these roles, so we simply don't pursue the opportunities?

Equally important to consider is whether patients and families want to be engaged.

Simply put, patient engagement makes for better research. Engaging patients in critical care medicine research requires a shift in thinking beyond the confines of what being a “patient” traditionally means. Researchers should view patient engagement not as another box to check to fulfill a mandate or fad, but rather as a valuable source of lived experience and knowledge from a perspective unknown to the scientist. Lived experience provides an understanding of what is important for patient care (i.e., priority setting), how to relate to patients and family members (i.e., when and how to approach for consent and data collection), data interpretation (i.e., what outcomes patients value), and dissemination (i.e., the best way to present results). Instead of just passive observers at the bedside, family members are valuable members along the patient's care journey, partners whose knowledge, opinions, and actions can lead to improved outcomes and satisfaction with care (3).

How Can Patients Be Meaningfully Involved in the Research Process?

Critical care medicine, like most specialties, excels in engaging patients and family

(Received in original form November 21, 2019; accepted in final form June 4, 2020)

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Ann Am Thorac Soc Vol 17, No 9, pp 1047–1051, Sep 2020

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DOI: 10.1513/AnnalsATS.201911-847IP

Internet address: www.atsjournals.org

Table 1. Goals of patient and researcher engagement in critical care medicine research

Goals	Learn/Inform	Participate	Consult	Involve	Collaborate	Lead/Support
Patient	To ask questions and learn about how to get more involved	To act as a subject or participant in a research study	To provide feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with researcher in all aspects of research	To make decisions and lead research activities
Researcher	To provide information, listen, and answer questions honestly	To act ethically and respectfully in the conduct of research	To seek patient input on an <i>ad hoc</i> basis	To include patients as standing members of an advisory group	To partner equally with patients as team members	To follow the patient's lead and support their decisions
How can this be done in critical care medicine?	Through orientation and information sessions and in media campaigns in an open atmosphere for sharing	Through quantitative, qualitative, or mixed methods research	Through Café Scientifiques, focus groups, priority-setting activities, and as members of <i>ad hoc</i> working groups or expert panels	Patients as members of standing working groups and research advisory committees	Patients as coinvestigators and research partners and as members of research steering committees	Through patient or community steering committees and patients as principal investigators

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members to participate in research (Table 1). Engagement of patients is more than participation in research studies (4), however; it is a meaningful partnership between patients and researchers working toward a common goal: improving processes and outcomes of care for critically ill patients and their family members. To achieve such an important goal, we must also consult, involve, collaborate, and support patients in critical care research.

Burns and colleagues (5) consulted with ICU patients and family members to inform the design of a trial of weaning from mechanical ventilation; patient and family member input was sought on an *ad hoc* basis to ensure that trial outcomes (e.g., ICU and hospital survival) were responsive to their priorities. Potestio and colleagues consulted with members of the public through a Café Scientifique (i.e., informal and accessible forum to bring together researchers and the public to discuss research) to establish priorities to improve critical care medicine (e.g., improvement in communication and provider well-being) (6). In the United Kingdom, Reay and colleagues used James Lind Alliance methodology to identify the top three priorities for research in intensive care medicine: early and appropriate identification of ICU patients; transition from ICU to home; and identification, management, and risks of delirium and

agitation (7). Both Haines and colleagues and Bell and colleagues involved family members as standing members of governance (8) and advisory (9) groups, engaging them as experts to guide critical care medicine organization and care concerns, respectively. The Institute of Medicine recommends the inclusion of patients and members of the public as both members of clinical practice guideline panels and external reviewers of the resultant documents (consult/involve) (10). This is essential to ensuring the relevance and applicability of clinical practice guidelines to the populations to which they are applied.

There is less evidence of research in the collaborate and lead/support domains: researchers in Canada have collaborated with family members as equal partners on the research team in a codesigned study of family-partnered delirium detection (e.g., family members of past ICU patients participated in priority setting, study design, and conduct recruitment) (11) and participated in projects led by patient researchers to identify opportunities for improving processes of care for critically ill patients (e.g., trained patient researchers conducted qualitative research to identify suggestions for improvements to ICU care) (12). In Australia, Haines and colleagues collaborated with patients and family

members to determine requirements for a peer support model for critical care survivors (13). More research into patient and family member engagement is desperately needed; most existing evidence is of low quality—we must use robust designs to evaluate the outputs of this effortful but worthy endeavor (14).

Building Capacity and Sustainability across the Spectrum of Engagement

Researchers should view patient engagement in research as an opportunity to enhance and diversify the skills of their team. By providing appropriate training, patient researchers will have the requisite skills to achieve sustainable results. Patient researchers should be encouraged to present to a variety of knowledge users, including other researchers and clinicians at research rounds and the public at open engagement sessions (e.g., Café Scientifique) (6), an open forum in an informal setting in which the public can learn about science and medicine and patient-identified forums of interest. Clinicians and decision makers will be exposed to patient engagement in research and should be trained in how to collaborate with various stakeholders. Patient researchers will be able to extend their

training and knowledge beyond the bounds of a singular project, training other patients and therefore further enhancing the patient-oriented focus of a research environment. We can all benefit from the inclusion of a diversity of perspectives and experiences, most notably that of the patient's and family members' lived experiences.

In which parts of the research process can patient researchers be engaged? We include patient researchers in all stages of research, including idea generation (through brainstorming sessions and pilot grant competitions), development of PICOD (population, intervention, comparison, outcome, and design) questions, grant writing, priority setting, data collection (including recruitment, informed consent, and questionnaire administration), project administration (always partnered with a scientist mentor), selecting outcomes of importance (e.g., in the context of clinical practice guidelines), interpreting findings, and disseminating results (e.g., creating lay summaries, graphical abstracts, and blog and social media posts).

How can a patient, family member, researcher, or clinician practically begin to pursue the engagement described herein? Meaningful patient engagement—involve, collaborate, lead/support on the spectrum (Table 1)—requires more time, resources, and money to enact. Many individuals do not know where to begin. In our experience, engaging interested patients occurs in one of three ways: 1) patients wanting to give back to the institution where they received care (i.e., their loved one was admitted to a local ICU); 2) referral by currently engaged patients (i.e., through support groups and other preexisting relationships); or 3) through knowledge translation activities, including public forums (e.g., open meetings, Twitter), news articles, and posting opportunities on affiliate webpages (e.g., Alberta Patient Engagement Platform [15], a resource to support researchers and patient partners in meaningful research engagement), where we discuss our research projects and the contributions made by patients. We suggest that a helpful way to begin engaging a

diverse group of patient researchers is by identifying multiple sources of recruitment.

The recruitment approaches described above are likely to attract a motivated patient researcher. These patients may be able to frame their thinking about research and care beyond their personal experiences to adopt a system-level lens. Our experiences with patient researcher engagement include mostly older (i.e., mostly retired), English-speaking, highly educated (i.e., at least one postsecondary degree) individuals with a history of consistent employment. Representation in patient engagement is usually from those with a similar viewpoint. It is also important to engage patient researchers from different backgrounds: those with a lay, nonprofessional background who frame their thinking about research and care on the basis of their own lived experience. These patients may have varying degrees of health literacy and come from culturally diverse backgrounds. Training and support for patient researchers will differ on the basis of their personal

Table 2. Potential pitfalls and mitigation strategies for patient engagement in research

Pitfall	Scenario	Mitigation Strategies
Initial engagement	Finding patients to engage is challenging.	Develop a register of interested patient researchers by providing consent forms for future contact during the ICU stay.
Training	To feel supported and in order to conduct rigorous science, patients should receive appropriate training for their roles, including expectation setting.	Formalized training programs for patient engagement in research exist (16). In the absence of these resources, patient researchers should be trained appropriately for their roles, which could include attending short courses, webinars, role-play activities, and shadowing. A mutual understanding of expectations (e.g., time commitment, outputs) should also be outlined.
Compensation	Some patient researchers do not wish to receive compensation for their time. Others, especially those committing substantial effort, desire remuneration.	Compensation should be guided by ethical and funder mandates (23, 24) and can take the form of cash or cash equivalents.
Privacy and confidentiality	Individuals without formal research training may not have the same appreciation for research ethical issues, including privacy and confidentiality.	Together with appropriate training for the role in which they are participating, patient researchers should also be trained in core ethical principles for conducting health research in humans (25).
Resistance	There may be resistance from administration, clinicians, and researchers for engaging family members in research.	Perceptions of increases in burden and risk (to each clinician, researcher, administrator, and family member) can be minimized through knowledge translation efforts, including education and engagement of a local champion.
Sustainability	The same individuals are always approached to participate. Patient researcher involvement should be evaluated regularly.	Relying on the same patients may result in burnout and dissatisfaction. Perspective may shift from patient/family partner to researcher over time.

Definition of abbreviation: ICU = intensive care unit.

experiences and backgrounds. Researchers and clinicians must remember that access to engagement opportunities will be limited for those who are systemically and structurally disadvantaged.

What role should healthcare systems and universities play in the recruitment, training, and ongoing support of patient researchers? To date, engagement has typically been initiated by individual research groups, though centralized and coordinated management would lend consistency and allow collaboration between a larger group of patient and academic researchers. Patients with experiences in specific conditions or areas, such as critical care medicine, cancer, and diabetes, could continue to be engaged by individual research groups, whereas those with general experiences could be engaged by healthcare systems and universities to support system-level initiatives (e.g., ethics review boards, funding review panels). Regardless of the area, to ensure sustained meaningful involvement, roles, responsibilities, and expectations should be discussed at the outset and regularly reviewed. It is important that patient researchers are afforded opportunities that align with their goals, which will be different for each person engaged. Researchers and clinicians would be well served by creating an inventory of different opportunities across the spectrum of engagement and providing options to interested patient researchers. The appropriate training should then be provided so that patient researchers feel supported and empowered to take on this new role. Training may include provision of the grant application, study materials, relevant journal articles, mock recruitment sessions, shadowing study staff, and paired opportunities with established patient researchers. Formal research training opportunities for patient researchers also

exist, including a successful program called PaCER (Patient and Community Engagement Research) in which they are trained to lead research projects through an established curriculum (16). Sustaining patient researcher involvement is as important as the initial engagement; we compensate patient researchers according to established guidelines (17), hold regular team-building events, and provide skill-building opportunities through paid conference and workshop attendance.

Patient engagement in critical care medicine research can occur at all stages of a project, from idea generation and grant writing to participant recruitment and knowledge dissemination. What we propose is in stark contrast to simply adding the name of a patient to a grant or committee. To avoid tokenism, engagement must be active throughout the entire research process and not simply validation of a previously created product. The most meaningful engagement will occur early in the research process to ensure that patient participation is not tokenistic, but rather the result of true collaboration, which takes time to build (18).

Pitfalls and Mitigation Strategies

The engagement of patients as researchers in critical care medicine is not without challenges (19). These challenges are often cited as reasons not to engage patients (4, 19). We prefer to view them as areas most worthy of effort and investigation; by overcoming these potential challenges, we can increase the impact and effectiveness of critical care medicine research. Table 2 presents pitfalls, scenarios, and mitigation strategies we have experienced to guide researchers in overcoming common

challenges to patient engagement. Outside of those described below, there are a number of other ethical and practical complexities to consider, including issues related to selection bias (risk of patients with polarizing views participating), liability, and engaging patients without incorporating their perspectives (i.e., tokenism) (20). We can learn from the implementation science literature on ways to surmount both individual and organizational challenges to engaging patients as researchers: educating staff, support from ICU leadership, and presentation of successful patient researcher engagement endeavors (3, 4, 21). There are myriad opportunities to advance the science of patient engagement in critical care research; as a community, we need to share our experiences, both good and bad, in order for this to occur.

Conclusions

Patients and their family members are central to research to improve patient care. Evaluative frameworks of patient engagement in critical care medicine research are lacking; until the time that these are formalized and validated, qualitative and survey-based assessments of engagement are highly valuable. Patients, family members, researchers, and clinicians should continue to report and disseminate their experiences with engagement to move the field forward. Patient engagement in research involves a shift in traditional thinking. Critical care medicine researchers can be leaders in this area if we are brave, bold, and open to change. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

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