



August 27, 2021

In response to the Patient-Centered Outcomes Research Institute (PCORI)'s [RFI](#) on five proposed National Priorities for Health, the American Geriatrics Society, with help from members of the Research Committee, has composed the following responses to the five proposed priorities. We hope our comments assist PCORI as they develop their research agenda.

Topics:	Comments:
<p>1. Increase Evidence for Existing Interventions and Emerging Innovations in Health</p> <p>PCORI aims to fund comparative effectiveness research on both new and existing healthcare approaches. This type of research compares two or more ways to prevent, diagnose, or treat a health condition. It can also compare ways to deliver health care. This research will help to close gaps in what is known, so that people have better information when making health decisions. Filling these gaps for both current and emerging approaches will improve health care, health outcomes, and health equity.</p> <ul style="list-style-type: none"> • What are the opportunities? • What are the challenges? • What is PCORI's unique role or contribution? • What does success look like? 	<p>PCORI has opportunities to support real world pragmatic trials specific to older adults in tandem with other funding agencies that are modeled on the recent STRIDE trail. In doing so, PCORI should be careful to ensure that research networks are constructed in a way that ensures inclusion of historically under-represented populations and heterogeneous populations with a range of health status, including those with multiple chronic conditions and functional changes (cognitive and physical).</p> <p>For older adults, it would be important for PCORI to consider studies that compare interventions with usual care. An example of usual care would be alerting a clinician that a medication that a patient is on is bad via fax and not providing guidance on alternatives. Another example is the lack of a whole person approach and coordination of care across specialties which can lead to poor outcomes particularly in people with multiple chronic conditions who see multiple specialists.</p>
<p>2. Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research</p> <p>PCORI aims to improve the nation's capacity for health research. Goals include expanding:</p> <ul style="list-style-type: none"> • The use of real-world data, such as health records or public health data, for research • The number and diversity of people and communities who lead or partner in research • Policies and practices that help people work together and learn from each other. <p>A strong infrastructure like this can improve the research process and lead to better study results. Doing so can improve the healthcare system and people's health.</p>	<p>The American Geriatrics Society (AGS) sees the use of health records as a way to improve health research as a huge challenge. The system can be opaque and is not specifically designed for research. We imagine there are people at multiple institutions trying to tackle this issue and that there may be an opportunity for institutions to learn from each other. Not having long wait periods (over a year) for a data request would be an example of a success.</p> <p>One potential resource for gaining a better understanding of how to harness the power of real-world data to inform research is the Department of Veterans Affairs (VA) Office of Electronic Health Record Modernization (OEHRM).</p>

<ul style="list-style-type: none"> • What are the opportunities? • What are the challenges? • What is PCORI’s unique role or contribution? • What does success look like? 	<p>Challenges include the slow progress in achieving interoperability between and across health systems; patchy nature of EHR adoption in long-term care settings; difficulties using medication data for research purposes, and difficulties in pulling data into data registries. An additional significant challenge to understanding the whole person is that data are captured by specialty/procedure and many Americans are cared for by clinicians in multiple settings with no EHR connectivity between those systems.</p> <p>An opportunity to address common EHR-related challenges would be the development and dissemination of standard templates to collect patient-reported outcomes or other health measures that matter to patients yet are not documented consistently (e.g., function, symptoms). Another opportunity is the validation of algorithms to extract proxies for these measures from the health record. A third opportunity is to support development of interoperability between disease-specific registries which would provide improved data on how the totality of care a person receives leads or does not lead to outcomes that matter to the patient.</p>
<p>3. Advance the Science of Dissemination, Implementation, and Health Communication</p> <p>PCORI aims to advance the science of, and practices that support, the real-world use of research results. In this way, research can better inform health decisions and improve health care and health. These efforts will look at how to best communicate about and share study results with diverse audiences. They will also look at ways to get results to patients, clinicians, and others to use in their health decisions.</p> <ul style="list-style-type: none"> • What are the opportunities? • What are the challenges? • What is PCORI’s unique role or contribution? • What does success look like? 	<p>The American Geriatrics Society (AGS) believes the push to create visual abstracts will be one way to improve communication of research results to diverse audiences.</p> <p>A significant challenge to conveying research results is that there is no widely used framework for sharing data with members of the public nor is their guidance as to the need to convey data in a way that does not lead to either overstatements or understatement of the risks and benefits. A current real-world case is how data from the aducanumab trials was reported out to the public.</p> <p>PCORI could play an important role in creating standards for communicating research results to the public that ensure that benefits are not over-stated and risks understated. This role could expand beyond science to include guidance for journalists and others who translate scientific findings for the public.</p>
<p>4. Achieve Health Equity</p> <p>PCORI aims to advance health equity in the United States. Health equity exists when all people have a fair and just opportunity to be healthy. Yet not all people and communities have such opportunities. Harmful societal policies and practices over generations have led to continued poor health. This affects people of color,</p>	<p>The American Geriatrics Society (AGS) believes there is a valuable opportunity here to expand the traditional focus of health equity to also promote equitable treatment and research that is inclusive of all older adults. Ageism remains a socially acceptable and widespread form of bias, and this has been reflected in scholarship by direct and indirect exclusion of older adults from research (thus making</p>

people with low income, and people with disabilities more than others. Advancing health equity requires partnering with these communities. It also involves building on and creating new ways to do, share, and use research to improve health.

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the results of uncertain applicability to this population), and by the relative neglect of outcomes that are of special importance to this population. For example, preservation of functional status, quality of life, goal-concordant care are all areas often neglected. This focus would add to, not replace, other important foci of health equity. These principles can and should be interlaced with the other priorities as well.

PCORI has played a critical role in increasing the inclusion of patients in the identification of important research questions and development of study designs that will lead to data that matters to patients. AGS believes that PCORI should continue to build on the work that it has been doing to better engage patients in identifying the research that is needed. One expansion that would be important to older adults is to prioritize engagement of family caregivers – particularly those who are caring for older adults.

Although we have made a great deal of progress in ensuring that research reflects community engagement, there is still a need to provide training to investigators as to how to meaningfully engage community members in a way that ensures that their voices are heard. In addition, more support is needed for training community members to be effective members of advisory boards and study partners. Attention should be given to helping both community members and investigators understand and break through the power structures that exist when bringing together lay people and highly trained and credentialed investigators. These structures are often invisible and difficult to navigate – even more so for people of color and for people with sensory or cognitive impairment.

One area where PCORI could play an important role is on the additional funding that is required to conduct truly inclusive research. There is a correlation between someone's ability to participate in a trial and their functional status as well as socioeconomic factors. A real world example is an older adult with mild cognitive impairment who is unable to get to a study site on their own and whose primary care giver works an hourly wage job and is unable to get time off to accompany them. Another example is a younger person with cancer who has a job with fixed hours and who is already grappling with time off that they might need for treatment. PCORI could lead efforts to redesign how we approach research design and implementation so that we are maximizing

	<p>participation regardless of socioeconomic status or functional limitations.</p>
<p>5. Accelerate Progress Toward an Integrated Learning Health System</p> <p>PCORI aims to support a learning health system, or LHS, that works to improve patients’ experience with health care and their health. Systems that affect people’s health—including health care, public health, and social services—often work independently. An integrated LHS can help these systems work together. To do so, it centers on what matters most to people and communities. A successful LHS depends on a feedback cycle to improve health care and health. This cycle engages communities, makes changes, learns from those changes, and repeats.</p> <ul style="list-style-type: none"> • What are the opportunities? • What are the challenges? • What is PCORI’s unique role or contribution? • What does success look like? 	<p>The American Geriatrics Society (AGS) believes that community-based services will be an important aspect of making progress toward an integrated learning health system. How can health systems work better with long term care facilities, clinicians who are not affiliated with the system, group practices, and FHQCs, agencies and centers serving older adults in the community, caregiving-focused organizations, home care services, and other services. Given patchwork funding, optimizing such supports to improve care is a challenge. Also, coming to consensus about what changes are needed poses another challenge.</p> <p>In terms of the health of the public, as exemplified by the recent COVID19 pandemic, there is a distinct lack of attention to the full range of older adults in national advice that is developed to guide states and communities.</p> <p>One opportunity for PCORI is to fund state-based learning networks that cut across health care, social services, private practice clinicians, and public health agencies. One important component of this approach is to recognize the need for a technology infrastructure that better connects people and also the pressing need to improve planning for disaster and other public health emergencies.</p>