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ICTR Pilot Grant Program Key Definitions and Terms for Community-Engaged Research RFAs

In addition to the definitions below, please refer to the definitions used by the **Wisconsin Partnership Program** per this link:

- <https://www.med.wisc.edu/media/medwiscedu/documents/service/wisconsin-partnership-program/grant-materials/wpp-definitions.pdf>

Adopter is an organization (community or health system) that takes up an innovation and implements it to benefit its target group (e.g. community members, patients).

Community (as defined by NIH for PA-08-077, Community Participation in Research R01) “refers to target populations that may be defined by: geography; race; ethnicity; gender; sexual orientation; disability, illness, or other health condition; or to groups that have a common interest or cause, such as health or service agencies and organizations, health care or public health practitioners or providers, policy makers, or lay public groups with public health concerns.”

Community-based organizations (as defined by NIH for PA-08-077, Community Participation in Research R01) refer to organizations that may be involved in the research process as members or representatives of the community. Possible community partners include, but are not limited to, Tribal governments and colleges, state or local governments, independent living centers, other educational institutions such as junior colleges, advocacy organizations, health delivery organizations (e.g., clinics, hospitals, and networks), health professional associations, non-governmental organizations, and Federally-qualified health centers.”

Comparative Effectiveness Research (CER). (1) “Generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care.” IOM (2009) (2) “The conduct and synthesis of research comparing the benefits and harms of different interventions and strategies to prevent, diagnose, treat and monitor health conditions in ‘real world’ settings.” (Federal Coordinating Council for Comparative Effectiveness Research: Report to the President and the Congress, June 30, 2009). (3) CER improves health outcomes by developing and dissemination evidence-based information to patients, clinicians and other decision-makers, responding to their expressed needs, about which interventions are most effective for which patients under specific circumstances.”

Dissemination, for the purposes of this RFA, is the targeted distribution of information and intervention materials to a specific audience (i.e., public health or clinical practice). The intent is to spread knowledge regarding an associated evidence-based intervention.

Dissemination Research is the scientific study of targeted distribution of information and intervention materials to a specific public health or clinical practice audience. The intent is to understand how best to spread and sustain knowledge and the associated evidence-based interventions.

End-user is the ultimate consumer of a finished innovation.

Engagement (in research). A bi-directional relationship between stakeholders and researcher resulting in informed decision-making about selection, conduct and use of research. Principles of engagement include: balanced representation among all groups; stakeholder understanding and acceptance of role; neutral, expert facilitations of discussions; connection among stakeholders; sustained stakeholder engagement. (Concannon. A new taxonomy for stakeholder engagement in patient-centered outcomes research. JGIM (2012); 27(8): 895-91.)

Health Disparities represent differences in the incidence, prevalence, mortality, burden of disease, and other adverse health conditions or outcomes that exist between population groups based on gender, age, race, ethnicity, socioeconomic status, geography, sexual orientation and identification, disability or special health-care needs, or other categories. Most health disparities are also considered to be health inequities – disparities that are avoidable, unfair or unjust and(or) are the result of social or economic conditions or policies that occur among groups who have persistently experienced historical trauma, social disadvantage or discrimination, and systematically experience worse health or greater health risks than more advantaged social groups.

Implementation is the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific settings.

Implementation Research is the scientific study of the use of strategies to adopt and integrate evidence-based health interventions into clinical and community settings in order to improve patient outcomes and benefit population health.

Implementer refers to those who implement the innovation within an organization.

Lifespan Research Translational research must study not only aggregate populations, but also focus on subpopulations with distinct characteristics, including the young and old, to uncover the interrelationships of disease phenotype with genomics, environmental exposures, health-related behaviors, and social factors across the lifespan. Significant evidence gaps remain in our understanding of childhood diseases, and of the effect of treatments on children. As a result, clinicians must often take action based on data from adults. Applicants should describe efforts to include children as a focus of translational research. With the “graying” of the US population, investigators must recognize and adapt to population longevity and the questions so driven and increase efforts to include older patients in research.

Patient-Centered Outcomes Research helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options. This research answers patient-centered questions such as:

- “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
- “What are my options and what are the potential benefits and harms of those options?”
- “What can I do to improve the outcomes that are most important to me?”
- “How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare?”

To answer these questions, patient-centered outcomes research:

- Assesses the benefits and harms of preventive, diagnostic, therapeutic, palliative, or health delivery system interventions to inform decision making, highlighting comparisons and outcomes that matter to people;
- Is inclusive of an individual's preferences, autonomy and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health related quality of life;
- Incorporates a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination; and
- Investigates (or may investigate) optimizing outcomes while addressing burden to individuals, availability of services, technology, and personnel, and other stakeholder perspectives.

Policy generally refers to a course or method of action that expresses guiding principles and objectives which are formulated by an organization to direct its actions in pursuit of goals. Policies are embodied in legislation, guidelines, regulations, or customary practice. Public policy refers to policies made by governmental entities at all levels. Organizations in both the public and private sectors are also managed via policies.

Purveyor is an organization that spreads an innovation and markets it, and trains others to adopt and implement it. It provides technical assistance to maximize high fidelity implementation and sustainability

Science of Community Engagement refers to research to identify the most effective approaches to community engagement and best practices in an experimental, data-driven fashion. The science of community engagement recognizes that we have yet to define optimal ways to involve relevant communities in each stage of the translational process.

Stakeholder refers to an individual or group who is responsible for or affected by health- and health-related decisions that can be informed by research evidence. Stakeholders are appropriate partners, investigators, consultants, and key personnel. Types of stakeholders can include: patients; nonprofessional caregivers; clinicians (e.g., physicians, nurses, pharmacists, counselors, and other providers of care and support services); patient-advocacy/parent groups; community groups; researchers; health-related associations; policy makers; and institutions, including organizational providers, purchasers, payers, and industry for whom the results of the research will be relevant.