

## A call for renaming clinical research partnerships

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In a recently published opinion piece in *BMJ Open*, "Rhetoric of Research: A Call for Renaming the Clinical Research Partnership," authors from Penn Nursing and Georgetown University School of



Nursing, present a compelling argument for rethinking the language used to describe participants in clinical research. The opinion calls for a shift from the traditional term "patient participant" to "participant partner," emphasizing the crucial role of participants in all facets of the research process.

The opinion piece traces the historical context of terms used to describe research participants. Initially referred to as "human subjects," the terminology evolved to "patients" and then to "patient participants." Despite these changes, the authors highlight that the existing terms suggest a power imbalance.

The authors, Anessa M. Foxwell, MSN, CRNP, ACHPN, doctoral student, and Connie M. Ulrich, Ph.D., RN, FAAN, Professor of Nursing and the Lillian S. Brunner Chair in Medical and Surgical Nursing, both from Penn Nursing; and Lillie LaRochelle, CNP, from Georgetown, argue this language does not properly reflect the value and contribution participants make to their studies.

The term "patient-participants" is seen as archaic because it sustains an authoritarian relationship in which researchers are regarded as holders of power while participants become dormant. The expression "participant partners" is meant to emphasize the partnership between researchers and those taking part in research, thus creating a more inclusive environment.

The report describes different clinical trials that prove the advantages of involving participants as research partners. The ADAPTABLE aspirin study and the CONNECT-HF trial, for example, embedded patients in advisory capacities to enhance recruitment messages, understand patient perspectives, and improve other overall trial outcomes. These are but a few examples that show how a partnership model can improve clinical research quality and impact.



The article provides several basic principles for using "participant partner" terminology:

- Dialogue and discourse: Involve relevant stakeholders in talks on the new terminology as well as its effects.
- Shared values: Formulate an arrangement based upon such things as reciprocity, solidarity, advocacy, procedural justice, and transparency.
- Inclusive participation: Ensure that participants and their caregivers participate in various stages of the process.
- Mutual support: Have an interface through which patients can share opinions with researchers.
- Transparent processes: Establish clear mechanisms for addressing ethical and other concerns during research.

The authors conclude that changing the rhetoric around patient participation is a small but significant step towards recognizing the true partnership in <u>clinical research</u>. By adopting the term "participant partner," the <u>research community</u> can take a meaningful step towards valuing those who contribute to scientific advancements.

**More information:** Anessa M Foxwell et al, Rhetoric of research: a call for renaming the clinical research partnership, *BMJ Open* (2024). DOI: 10.1136/bmjopen-2023-080137

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