

US Deprescribing Research Network Stakeholder Engagement Frequently Asked Questions (FAQ)

The US Deprescribing Research Network Pilot Proposal Guidelines requires a stakeholder engagement component. Participation from at *least one* stakeholder, either in an **advisory capacity or as a full member of the research team**, is required.

Why is Stakeholder Engagement Important to Research?

Direct stakeholder engagement is essential to ensure stakeholder knowledge, insights and perspectives are equitably represented to enhance the relevance and use of the research.

Engagement builds:

- **Trust** - boosts research to be more inclusive and trustworthy
- **Shared learning** - enhances the real-life value of studies for both the researcher and the community being served
- **Knowledge among end-users** - addresses misconceptions about deprescribing
- **Shared decision-making** – promotes collective understanding of research results by patients and those who care/advocate for them
- **Relationships and connections** - helps to develop messaging and ways to disseminate findings
- **Capacity to act** - enables patients and healthcare partners to apply research findings quickly and leverage change

Who is a Stakeholder?

Stakeholders may include:

- Patients/Consumers (with lived experience) representative of the population of interest in the particular study (*important not to confuse patient subjects with patient stakeholders*)
- Patient Family/Caregivers
- Organizations who serve and/or advocate for study population
- Other stakeholders representing professional experience include but not limited to: clinicians, community members, healthcare purchasers, payers, industry, hospital and other health systems, policy makers,

Note that engaging with USDeN alone does not constitute a stakeholder engagement component.

How do you decide on what kind of stakeholder(s)?

In general, including all relevant types of stakeholders is a good idea. Describing the rationale for the type(s) of stakeholder involvement you propose is important. For [example](#), an intervention designed to improve outcomes for older adults with diabetes mellitus should consider including older adults with diabetes mellitus as stakeholders. If the intervention is conducted through a primary care clinic, the perspectives of primary care physicians, allied health professionals, and staff in the clinic may also be important.

What is Engagement in Research?

Engagement in research is the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process—from planning the study, to conducting the study, and disseminating study results.

How might I include a stakeholder component in my study?

This can include but is not limited to:

- patient and/or surrogate decision-maker interviews;
- focus groups,
- an advisory group that includes a relevant organization and/or patient representatives
- including stakeholders as co-investigators who are equal partners in the project

These forms of engagement can be used to inform one or more aspects of the proposed research, for example research question, study or intervention design, participant recruitment strategies, interpreting findings, and/or disseminating results. Engagement does not have to be extensive for all studies, but each proposed study should have at least one form of engagement.

How do you Measure Effective Stakeholder Engagement?

There are numerous ways to measure stakeholder engagement such as surveys and assessments. Existing resources and examples can be found at the [PCORI engagement tool and resource repository](#).

Should you compensate for Stakeholder Engagement?

For genuine involvement of Stakeholders there should be compensation for their expertise, time and contributions. PCORI's [Compensation Framework](#) provides guidance for establishing fair compensation levels for patients, caregivers, and other stakeholders.

Where can I find additional information?

[Patient-Centered Outcomes Research Institute](#) (PCORI) provides many resources that expand upon questions answered above with additional tools.