PLEX Engagement in Research Community of Practice

May 2026: Partnering for Polycystic Ovary Syndrome (PCOS) Research: Insights from the PCOS Patient Advisory Council (PPAC)

This document provides a summary of engaging people with lived experience (PLEX) in an advisory council.

***Note PCOS has recently been renamed to Polyendocrine Metabolic Ovarian Syndrome (PMOS).**

Key Presentation Points

- The development of the PPAC reflected a critical need for research to reflect the lived experience of people living with PMOS
- The PPAC was formed over fourth months via a general call, informational webinars, and interviews
- The PPAC met virtually and contributed to elements such as study advertisements and data interpretation

What did we discuss?

- **Maintaining Communication:** Teams need to actively and frequently maintain communication with PLEX partners to facilitate meaningful engagement. One strategy is beginning meetings with check-ins.
- **Skill-Building:** Provide opportunities for PLEX to gain skills throughout the research process through skills workshops.
- **Onboarding Considerations:** Finding the right time to add new PLEX members to the PPAC and providing support in bringing them up to speed on the current project/initiative is an important aspect on onboarding.
- **Diverse PLEX:** The team will continue to focus efforts on capturing and including a greater diversity in age, location, ethnicity and race in the PPAC going forward.
- **Evaluation:** An important step in evaluating PLEX engagement in research is identifying and reviewing existing evaluation tools to determine what may be appropriate and best suited for evaluation for your specific population and engagement activities.

Relevant Resources on PLEX Engagement in Research:

1. EMBRACE Women's Health Lab: A link to the EMBRACE lab website.
2. From PCOS to PMOS: A link to an article in the Conversation about the PCOS to PMOS name change.