



FNIH

Foundation for the National Institutes of Health

Building Bridges to Breakthroughs: Patient Engagement at the Foundation for the NIH

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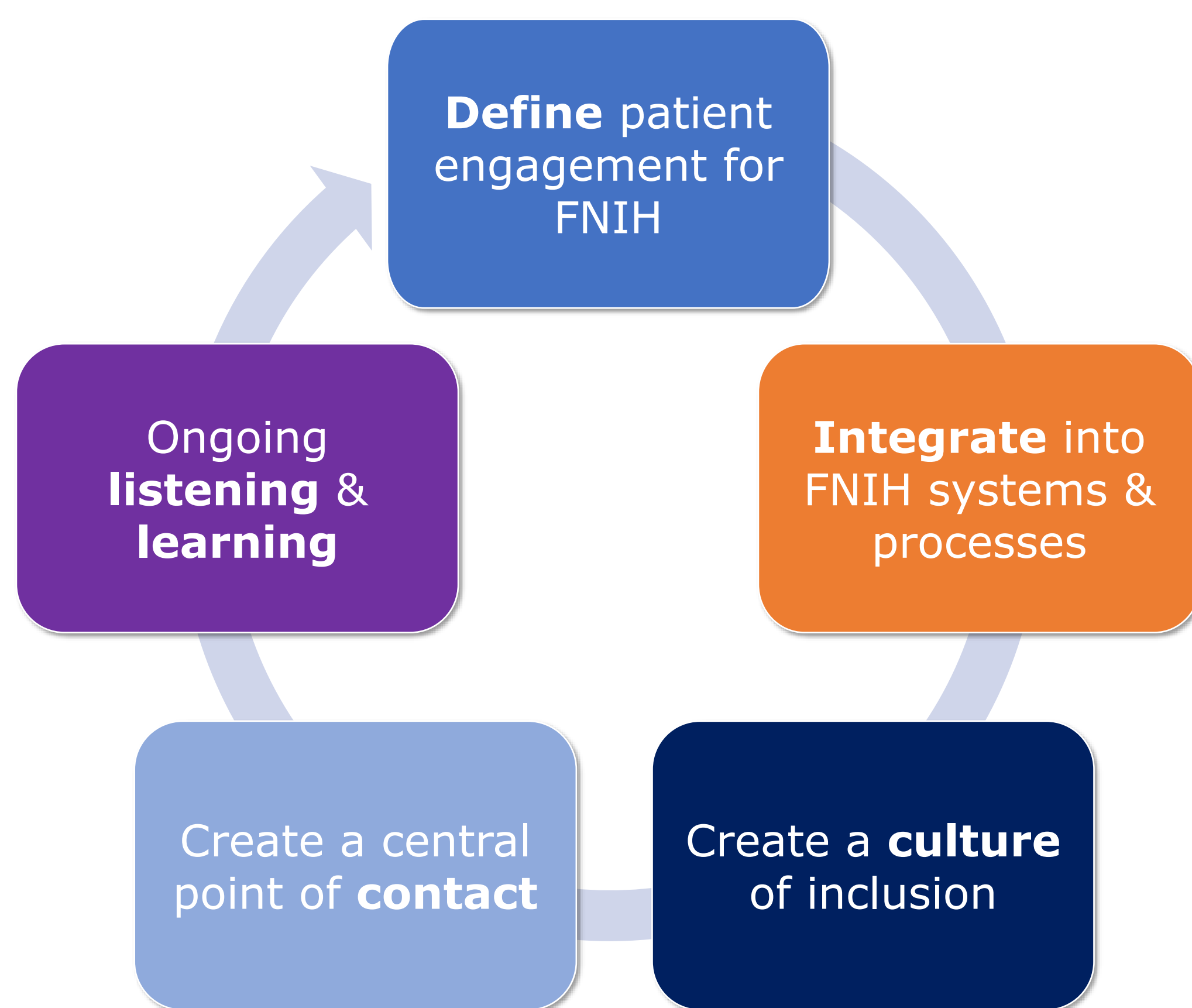
Executive Summary

The Foundation for the National Institutes of Health (FNIH) teams up with NIH experts, leading academics, and private sector partners to accelerate medical breakthroughs. We prioritize patient-centered work, valuing the insights of people with lived experience (PWLE). By doing this, we believe we can improve patients' lives. While FNIH excels at bringing diverse stakeholders together, there's room to involve patients and patient groups more actively, as they are the ultimate beneficiaries of medical research.

Audience

The FNIH's Patient Engagement efforts are aimed toward **patients, researchers, drug developers, industry, nonprofits, advocacy groups, academia, and regulatory agencies.**

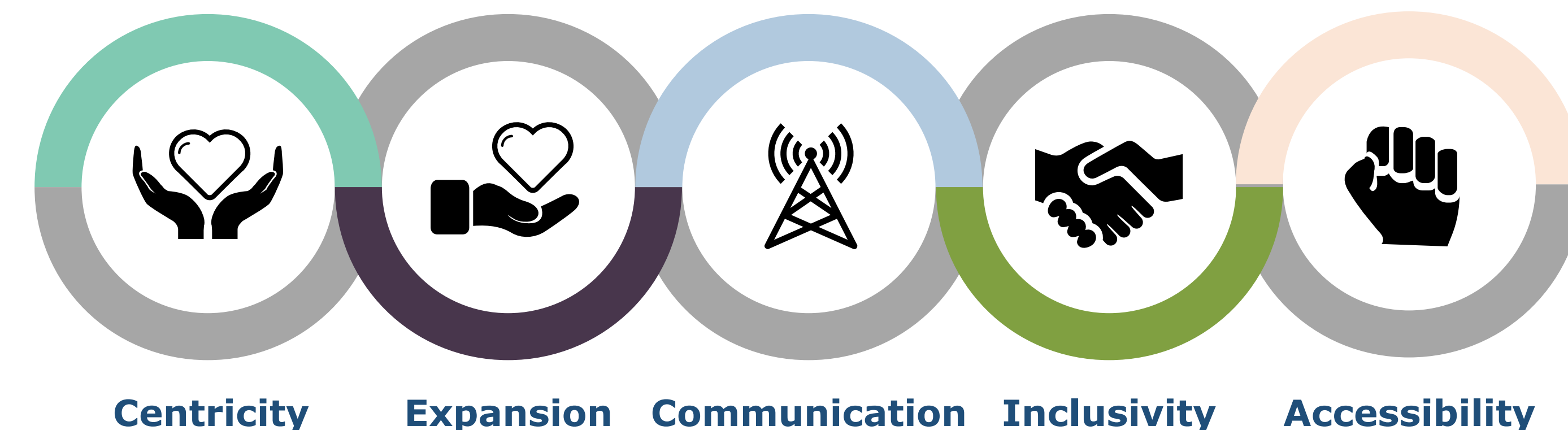
Patient Engagement Strategy



The FNIH aims to incorporate the perspectives of PWLE into **every step of our project process**:

1. Concept Generation
2. Concept Qualification and Refinement
3. Program Development
4. Launch
5. Dissemination

Our Principles



Key Accomplishments

- Established a **Patient Engagement Council (PEC)** to guide the FNIH Patient Engagement Plan, including representatives from nonprofit advocacy groups, **FDA, NIH, PCORI, BIO, NHC, and the Milken Institute**
- Launched a Patient Ambassador program featuring individuals who have engaged in FNIH research programs, advocating for our initiatives externally



Findings

- **Prioritize leveraging PEC and the FNIH Patient Engagement team expertise** to support research teams throughout project development and launch
- Emphasize the need to incorporate inclusion of PWLE engagement in budget allocation to support PWLE activities during budget development step
- **Ensure that results are communicated in a "health-literate manner,"** as universally requested by PWLEs and advocacy groups.
- **Elevate the involvement of PWLEs** and advocacy groups in **project steering, leadership, and publications**
- **Review all new concepts for meaningful and early engagement with the community and patients**
- Improve FNIH website and communications to **better serve the needs of patients**
- **Integrate patient representation into every monthly all-hands meeting** to increase patient centricity as an organization
- Actively participate in external patient conferences to **amplify patient voices**

Next Steps

- September 11, 2024 – 2nd FNIH Patient Summit
- September 16, 2024 – Patient Panel at FNIH Science Day
- Development of a Patient Orientation program
- Building additional Patient Ambassadors
- Building a sustainable Community Engagement approach
- Evolving the FNIH patient engagement plan through survey feedback