



Creating a Data Infrastructure for Patient-Centered Outcomes Research

Introduction and Overview

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Creating a Data Infrastructure for PCOR Agenda

- Introduction and Overview – Stephanie Garcia
- Structured Data Capture (SDC) Project Overview – Farrah Darbouze
- Data Access Framework (DAF) Project Overview – Farrah Darbouze
- Patient Matching, Aggregation and Linking (PMAL) Project Overview – Debbie Bucci
- Patient Generated Health Data (PGHD) Project Overview – Michelle Murray
- Privacy and Security for PCOR (PSP) Project Overview – Devi Mehta
- Q & A/Wrap Up

Patient-Centered Outcomes Research (PCOR) Overview

- The Affordable Care Act of 2010 established the [Patient Centered Research Trust Fund \(PCORTF\)](#) to support comparative clinical effectiveness research
- *The PCOR data infrastructure is an integrated electronic environment designed to engage patients in healthcare decision-making and incorporate their responses into research.*
- *This infrastructure is intended to support the evolving demands for health information as well as emerging and promising health technologies.*

- **Recently ended**

- » Structured Data Capture (SDC)
- » Data Access Framework (DAF)

- **Ongoing**

- » Patient Matching, Aggregating, and Linking (PMAL)
- » Patient-Generated Health Data (PGHD)
- » Privacy and Security Landscape and Blueprint (Privacy and Security)

- **Recently launched**

- » Patient Reported Outcomes (PRO)
- » Coordinated Registry Network for Women's Health Technologies
- » Harmonization of Various Common Data Models and Open Standards for Evidence Generation



The Office of the National Coordinator for
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Thank you!

Go to <http://healthit.gov/PCOR> for more information

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