RESEARCH READY QUICK REFERENCE GUIDE

NORD®
National Organization for Rare Disorders

General Information

- **National Center for Advancing Translational Sciences (NCATS)**
  ncats.nih.gov
- **Institutional Review Boards (IRB)**
  bit.ly/Institutional-Review-Boards
- **Patient-Centered Outcomes Research Institute (PCORI)**
  pcori.org
- **IAMRARE™: NORD's Registry Program**
  bit.ly/NORD-IAMRARE
- **Agency for Healthcare Research and Quality (AHRQ)**
  ahrq.gov
- **General Data Protection Regulation (GDPR)**
  gdpr.eu
- **Rare Diseases Clinical Research Network (RDCRN)**
  rarediseasesnetwork.org
- **Health Insurance Portability and Accountability Act (HIPAA)**
  bit.ly/HIPAA_Index

Registry Guidance

- **Research Fundamentals (PCORI)**
  bit.ly/PCORI_Research_Fundamentals
- **Registries for Evaluating Patient Outcomes: A User's Guide (AHRQ)**
  bit.ly/Registries-for-Evaluating-Patient-Outcomes
- **RaDaR (NCATS)**
  ncats.nih.gov/radar
- **10 Key Principles for Rare Disease Patient Registries**
  (Produced by NORD, CORD and EURORDIS)
  bit.ly/Principles-for-Rare-Disease-Patient-Registries

Portals

- **Medline**
  medlineplus.gov
- **National Library of Medicine**
  bit.ly/National-Library-for-Medicine

Studies

- **Where to find ongoing studies:** clinicaltrials.gov
- **Where to read published studies:** bit.ly/PubMed-Studies

Funding Opportunities

- **NCATS Open Funding Opportunities**
  bit.ly/NCATS-Funding
- **RDCRN Opportunities**
  bit.ly/RDCRN-Opportunities
- **PCORI Funding Opportunities**
  pcori.org/funding-opportunities

Phases of Clinical Research

- **RDCA-DAP 5 Steps of the Drug Development Process Graphic**
  bit.ly/RDCA-DAP-Drug-Development-Process

Stakeholder Engagement Resources

- **Clinical Trials Transformation Initiative (CTTI):** Brings together academia, clinical investigators, government and regulatory agencies, industry, institutional review boards and patient advocacy groups to develop evidence-based solutions to clinical research challenges
  ctti-clinicaltrials.org
- **FDA-led Patient-Focused Drug Development (PFDD) Meetings:** Public meetings to obtain the patient perspective on diseases and their treatments
  bit.ly/FDA-PFDD-Meetings
- **Externally-led PFDD Meetings:** Allows patient organizations to organize patient-focused collaborations to generate public input on other disease areas, using the process established through FDA-led PFDD meetings as a model
  bit.ly/External-PFDD-Meetings
- **NORD MOU Pilot Listening Sessions:** Pilot listening sessions to inform FDA staff of disease and treatment burden in rare diseases
  bit.ly/MOU-Listening-Sessions
- **Patient Engagement Collaborative (PEC):** A forum to discuss and share experiences on patient engagement in medical product development and regulatory discussions
  bit.ly/Patient-Engagement-Collaborative
- **Patient Engagement Advisory Committee (PEAC):** Provides advice to the Commissioner or designee, on complex issues relating to medical devices, the regulation of devices and their use by patients in a public advisory committee meeting
  bit.ly/Patient-Engagement-Advisory-Committee
- **Patient Representative Program (PRP):** FDA Patient Representative consultants provide direct input to inform the agency's decision-making associated with medical products for drugs, biologics and medical devices in a public advisory committee meeting or as part of agency-directed assignments
  bit.ly/Patient-Representative-Program
- **PCORI Advisory Panel on Rare Disease:** Advises and provides recommendations to PCORI's Board of Governors, Methodology Committee and staff on the conduct of patient-centered comparative clinical effectiveness research in rare diseases and on coordination and engagement with the rare disease research community
  bit.ly/Advisory-Panel-Rare-Disease

Diversity, Equity and Inclusion Resources

- **"How to Plan Your Research Through Multi-Stakeholder Engagement and Strategic Planning?"** -Dr. Teneasha Washington, PhD, MPH
  bit.ly/Engagement-Strategic-Planning
- **BoardSource: Diversity, Inclusion and Equity Resources**
  bit.ly/BoardSource-Resources
- **Enhancing the Diversity of Clinical Trial Populations — Eligibility Criteria, Enrollment Practices and Trial Designs Guidance for Industry**
  bit.ly/Clinical-Trial-Populations

Additional Resources

- **NIH Research and Training**
  nih.gov/research-training
- **Establishing Patient Registries for Rare Diseases: Rationale and Challenges**
  bit.ly/Establishing-Patient-Registries