⭐Helpful Tip: Use Ctrl + F to search a term		
Acronym	**Term**	**Definition**
	Accountability	The responsibility of program managers and staff to provide evidence to stakeholders and funding agencies that a program is effective and in conformance with its coverage, service, legal, and fiscal requirements. https://cdc.gov/evaluation/guide/glossary/index.htm
	Accuracy	The extent to which an evaluation is truthful or valid in what it says about a program, project, or material. https://cdc.gov/evaluation/guide/glossary/index.htm
ACO	**Accountable Care Organization**	ACOs are groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high-quality care to their Medicare patients. https://www.medicare.gov/manage-your-health/coordinating-your-care/accountable-care-organizations
	Activities	The actual events or actions that take place as a part of the program .https://cdc.gov/evaluation/guide/glossary/index.htm
AO	**Administrative Official**	The individual within the submitting organization/institution who is responsible for the proper administration of the contract, including, but not limited to, overseeing the submission of the contract activation, contract renewals, and additional materials required by the granting agency's policies and procedures. https://www.pcori.org/funding-opportunities/what-you-need-know-apply/glossary
	Administrative Review	An initial review conducted by CRN staff to assess feasibility including budget, IRB approval, legal agreements, utilization needs. https://starcrn.org/frequently-asked-questions/
AE	**Adverse Event**	A drug reaction is also known as a side effect, is any undesirable experience associated with the use of a medicine in a patient. Adverse events can range from mild to severe. Serious adverse events are those that can cause disability, are life-threatening, result in hospitalization or death, or are birth defects. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms
AHRQ	**Agency for Healthcare Research and Quality**	The Agency for Healthcare Research and Quality's (AHRQ) mission is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used. AHRQ priorities are described. https://www.ahrq.gov/cpi/about/mission/index.html
	Allowable Costs	A cost that is approved within the budget and is not otherwise unallowable under the Funded Research Policies. A direct cost is allocable to the project if the goods or services involved are chargeable or assignable to the project in accordance with relative benefits received or other equitable relationship. As a result, a cost is allocable to the funded project if (1) it is incurred solely to advance the work under the project, or (2) it benefits both the funded project and other work of the

		recipient organization, in proportions that can be approximated through use of reasonable methods. https://www.pcori.org/glossary
ADOS	**American Descendants of Slavery**	Refers to descendants of enslaved Africans in the United States (from its colonial period onward) and the political and social movement whose purpose is to advocate for reparations, the idea of compensating those who have been wronged, on behalf of Black Americans. https://www.adosfoundation.org/
AKI	**Acute Kidney Injury**	Acute kidney injury (AKI), also known as acute renal failure (ARF), is a sudden episode of kidney failure or kidney damage that happens within a few hours or a few days. AKI causes a build-up of waste products in your blood and makes it hard for your kidneys to keep the right balance of fluid in your body. AKI can also affect other organs such as the brain, heart, and lungs. Acute kidney injury is common in patients who are in the hospital, in intensive care units, and especially in older adults.https://www.kidney.org/atoz/content/AcuteKidneyInjury
API	**Asian/Pacific Islander**	All people of Asian, Asian American or Pacific Islander ancestry who trace their origins to the countries, states, jurisdictions and/or the diasporic communities of these geographic regions. https://www.api-gbv.org/resources/census-data-api-identities/
AANHPI	**Asian American and Native Hawaiians/Pacific Islander**	
AAPI	**Asian American/Pacific Islander**	
APIDA	**Asian Pacific Islander Desi American**	A pan-ethnic classification that intentionally includes South Asians (Desi) as part of the community. There is a great diversity of identities and ethnicities encompassed under the APIDA umbrella, including East Asian, South Asian, Southeast Asian, and Pacific Islander. This term ultimately includes all people of Asian, Asian American and Pacific Islander ancestry who trace their origins to the countries, states, jurisdictions and/or the diasporic communities of these geographic regions. CSUSM-Who is APIDA?.
AWS	**Amazon Web Services**	Amazon Web Services, Inc. is a subsidiary of Amazon that provides on-demand cloud computing platforms and APIs to individuals, companies, and governments, on a metered, pay-as-you-go basis. Clients will often use this in combination with autoscaling. https://aws.amazon.com/what-is-aws/
	Attributes	Attributes of a medical device are features such as effectiveness, safety, tolerability, means of implantation/use, duration of the effect, duration of use, frequency of use, lifestyle aspects of use, and other device characteristics that impact benefit-risk considerations. https://live-mdic.pantheonsite.io/wp-content/uploads/2016/04/Patient-Preference-Study-Design-20171102.pdf
	Attribution	The estimation of the extent to which any results observed are caused by a program, meaning that the program has produced incremental effects.https://cdc.gov/evaluation/guide/glossary/index.htm
	Awardee	An organization/institution that has received a grant award. https://www.pcori.org/glossary
BAA	**Business Associate Agreement**	A “business associate” is a person or entity, other than a member of the workforce of a covered entity, who performs functions or activities on behalf of, or provides certain services to, a covered entity that involve access by the business associate to protected health information. A “business associate” also is a subcontractor that creates, receives, maintains, or transmits protected health information on behalf of another business associate.

		https://www.hhs.gov/hipaa/for-professionals/covered-entities/sample-business-associate-agreement-provisions/index.html
	Benefit, Harm, and Risk	**Benefit** is a favorable effect or desirable outcome of a diagnostic or therapeutic strategy. **Harm** is an unfavorable effect or desirable outcome of a diagnostic or therapeutic strategy. **Risk** is defined as the qualitative notion of the probability and/or severity of a particular harm. This definition accommodates how the term "risk" is used in much of the benefit-risk literature and prior FDA CDRH guidance.https://neac.health.govt.nz/national-ethical-standards/part-two/8-research-benefits-and-harms/
	Biosketch	A profile of the experience and accomplishments of the key personnel in an application. https://www.pcori.org/glossary
	BioVU	Vanderbilt's collection of de-identified DNA samples whose associated clinical data elements are stored in the Synthetic Derivative (SD) https://victr.vumc.org/what-is-biovu/
BIPOC	**Black, Indigenous, and people of color**	In the U.S., **Black,** can refer to dark-skinned peoples of Africa, Oceania, and Australia or their descendants without regard for the lightness or darkness of skin tone https://www.namilexington.org/bipoc/**. Indigenous**, refers to ethnic groups native to the Americas. **People of color** (not to be confused with the pejorative "colored people") is an inclusive and unifying term across different racial and ethnic groups. While "people of color" can be a politically useful term and describes people with their own attributes (as opposed to what they are not, e.g., "non-white"), it is also important whenever possible to identify people through their own racial/ethnic group, as each has its own distinct experience and meaning and may be more appropriate.https://www.nea.org/professional-excellence/student-engagement/tools-tips/racial-justice-education-key-terms-and
	Boxed Warning	This type of warning is also commonly referred to as a "black box warning." It appears on a prescription drug's label and is designed to call attention to serious or life-threatening risks. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms
BPS	**Broad Pragmatic Studies**	intended to avoid confusion for potential applicants about which funding opportunity is most appropriate for their research proposal and assist applicants in their long-range research planning with the broader range of study size options under the two funding level categories Broad Pragmatic Studies Funding Announcement -- 2022 Standing PFA | PCORI
	Breadth	The scope of the measurement's coverage.https://cdc.gov/evaluation/guide/glossary/index.htm
	Burden	The frequency of the condition, the expected mortality and morbidity, and/or the degree of suffering associated with symptoms, complications, or other consequences of the condition. Additionally, it may include the costs to the US population of healthcare services used, the individual patient's out-of-pocket expenses, as well as intangible costs to the patient, such as time away from paid or unpaid occupations. https://www.pcori.org/glossary

CAB	**Community Advisory Board**	A type of advisory board consisting of representatives of the general public who meet with representatives of an institution to relay information between the two groups. CABs are especially associated with clinical research and are an aspect of community-based participatory research. CABs provide advice, and researchers who consult with CABs get information which they would not otherwise get about the target community demographic which they are researching.https://research.musc.edu/resources/sctr/programs/community-engagement/translational-research-community-advisory-board
CVD	**Cardiovascular Disease**	Also called heart disease is a class of diseases that involve the heart, the blood vessels (arteries, capillaries, and veins) or both https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#C-1
	Care Transitions	The movement patients make between different health care providers or setting to another. https://www.pcori.org/glossary
K12	**Career development grant**	The National Institutes of Health (NIH) K12 is a training and career development grant in which candidate positions are filled at the discretion of the institution, and assignment of candidate positions is generally not known at the time of application or at the time of an award. https://researchtraining.nih.gov/programs/career-development
	Case Study	A data collection method that involves in-depth studies of specific cases or projects within a program. The method itself is made up of one or more data collection methods (such as interviews and file review).https://cdc.gov/evaluation/guide/glossary/index.htm
	Causal Inference	The logical process used to draw conclusions from evidence concerning what has been produced or "caused" by a program. To say that a program produced or caused a certain result means that, if the program had not been there (or if it had been there in a different form or degree), then the observed result (or level of result) would not have occurred.https://cdc.gov/evaluation/guide/glossary/index.htm
CBPR	**Community Based Participatory Research**	Community-based participatory research (CBPR) is an applied collaborative approach that enables community residents to more actively participate in the full spectrum of research (from conception – design – conduct – analysis – interpretation – conclusions – communication of results) with a goal of influencing change in community health, systems, programs or policies. Community members and researchers partner to combine knowledge and action for social change to improve community health and often reduce health disparities. Academic/research and community partners join to develop models and approaches to building communication, trust and capacity, with the final goal of increasing community participation in the research process. It is an orientation to research which equitably involves all partners in the research process and recognizes the unique strengths that each brings.Community-based Participatory Research (CBPR): Towards Equitable Involvement of Community in Psychology Research - PMC (nih.gov)
CDC	**Centers of Disease Control**	CDC is the nation's leading science-based, data-driven, service organization that protects the public's health. For more than 70 years, we've put science into action to help children stay healthy

		so they can grow and learn; to help families, businesses, and communities fight disease and stay strong; and to protect the public's health. https://www.cdc.gov/about/
CDRH	**Center for Devices and Radiological Health**	Assures that patients and providers have timely and continued access to safe, effective, and high-quality medical devices and safe radiation-emitting products. https://www.fda.gov/about-fda/fda-organization/center-devices-and-radiological-health
CDRN	**Clinical Data Research Network**	*Former name for Clinical Research Network (CRN) https://www.pcori.org/glossary
CDW	**Clinical Data Warehouse**	Clinical business intelligence tools such as clinical data warehouse enable health care organizations to objectively assess the disease management programs that affect the quality of patients' life and well-being in public. https://pubmed.ncbi.nlm.nih.gov/28938242/
CEO	**Chief Executive Officer OR Chief Engagement Officer**	As more CEOs get on board and lead a strategic and systematic approach to engaging all stakeholders, those at large organizations will either accept responsibility for the role of Chief Engagement Officer with the support of a single executive or will need to put someone in charge of the effort. https://enterpriseengagement.org/knowledge/content/8633563/the-role-of-the-chief-engagement-officer/
CHSR	**Vanderbilt Center for Health Services Research**	The Vanderbilt Center for Health Services Research mission is to improve the quality and equity of healthcare delivery and health outcomes for all people through translational research and training initiatives, bridging the gap between evidence and real-world practice. https://www.vumc.org/hsr/center-health-services-research
CIO	**Chief Information Officer**	oversees the information technology needs of a company. https://northwest.education/insights/careers/duties-and-responsibilities-of-a-cio-chief-information-officer/
CKM	**VUMC Center for Knowledge Management**	Engages in the collection, translation, and curation of external and internal knowledge and data, to best inform and document the decision processes of VUMC. https://ckm.vumc.org/ckm/
CMIO	**Chief Medical Information Officer**	A chief medical information officer, sometimes called an "informatics" officer or director, is a healthcare executive who is responsible for a healthcare organization's design, implementation and use of technology. https://www.healthinformaticsdegrees.org/faq/what-is-a-chief-medical-information-officer/
CTSA	**Clinical and Translational Science Awards**	A type of U.S. federal grant administered by the National Center for Advancing Translational Sciences (NCATS), part of the National Institutes of Health (NIH). The Clinical and Translational Science Awards (CTSA) program supports a national network of medical research institutions — called hubs — that work together to improve the translational research process to get more treatments to more patients more quickly. https://ncats.nih.gov/ctsa/
CER	**Clinical Effectiveness Research**	Compares two or more medical treatments, services, or health practices to help patients and other stakeholders make better informed decisions. https://www.pcori.org/about/about-pcori/our-programs/clinical-effectiveness-and-decision-science

	Clinical Practice Guidelines	Systematically developed statements or recommendations to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. They present indications for performing a test, procedure, or intervention, or the proper management for specific clinical problems. Guidelines may be developed by government agencies, institutions, organizations such as professional societies or governing boards, or by convening expert panels. https://www.pcori.org/glossary
	Clinical Research	Clinical research is medical research that involves people to test new treatments and therapies. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
CRN	**Clinical Research Network**	A network of institutions under PCORnet with a goal of transforming data gathered from routine patient care across their participating health systems into a consistent format, the PCORnet Common Data Model, to enable rapid response to research-related questions. Patient partners participate in PCORnet governance as well as all phases of the research process. https://starcrn.org/frequently-asked-questions/
	Clinical Trial	A research study in which one or more human subjects are prospectively assigned to one or more interventions (which may include placebo or other control) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
	ClinicalTrials.gov	An online registry of clinical trials that are being conducted around the world. ClinicalTrials.gov is operated by the National Library of Medicine at the National Institutes of Health and can be accessed by anyone who has access to the internet. https://clinicaltrials.gov/
Co-I	**Co-Investigator**	A PCORI term to identify an individual recognized by the prime institution and the principal investigator (PI) as someone making a significant contribution to a project. The Co-I is an individual who the PI relies on to assume responsibilities related to the execution of the project and to commit a specified percentage of time to the project. A Co-I is considered “key personnel” and may be employed by or formally affiliated (through written agreement) with the prime institution or a collaborating institution. The patient and/or stakeholder partner may be listed as a Co-I. The designation of a Co-I does not affect the PI’s roles and responsibilities nor does it imply a Dual PI Award. https://grants.nih.gov/grants/glossary.htm#C
CRGs	**Collaborative Research Groups**	These groups are composed of content experts from within PCORnet focused on generating high-priority, engaging research questions to leverage PCORnet’s unique infrastructure. The CRGs collaborate with stakeholders including patients, caregivers, advocacy groups, providers, and funders early on to move research forward more quickly and more efficiently. https://www.pcori.org/glossary
	Commons	The Commons is a public website fostering connection, communication, learning, and engagement among people involved in clinical research. On the PCORnet Commons, you can share and access resources, engage in dialogue, and connect with colleagues. https://starcrn.org/frequently-asked-questions/

CDM	**Common Data Model**	Each site's EHR data is housed in a data warehouse. The design of this warehouse and what it contains is the same at each site making it a common model among all sites for housing data. More succinctly, the CDM is a way of organizing data into a standard structure across sites. https://starcrn.org/frequently-asked-questions/
CBCT	**Community Based Clinical Trials**	clinical trial conducted primarily through primary-care physicians, community health centers, and local outpatient facilities rather than academic research centers. https://www.centerwatch.com/health-associations/glossary
CEnR	**Community Engaged Research**	is a framework or approach to research, not a methodology. It involves building authentic partnerships between researchers and community organizations and recognizes the strengths of community Organizations and individuals and builds on those strengths. A community-engaged study may incorporate both qualitative and quantitative methods. What characterizes community-engaged research is not the methods used, but the principles that guide research and the relationships between researchers and the community https://www.niehs.nih.gov/research/supported/translational/community/index.cfm
CERC	**Community Engaged Research Core**	A partnership between Meharry Medical College and the Vanderbilt University Medical Center which brings academic and community partners together to improve community health and healthcare through research. CERC shapes and supports innovative and translational community-engaged research by preparing scientists to impact the public's health, building the capacity for communities to engage in research and creating transformative strategies and structures to support academic-community partnerships. https://victr.vumc.org/meharry-vanderbilt-community-engaged-research-core/
CES	**Community Engagement Studio**	A consultative session for researchers interested in getting input on their work from patients, caregivers, health care providers, community members and other non-researcher stakeholders. A panel of stakeholders (whose characteristics are defined by the researcher) will be assembled to provide feedback to enhance the planning, design, implementation, translation or dissemination of your research. https://victr.vumc.org/community-engagement-studio/
CHW	**Community Health Worker**	Trained public health workers who serve as a bridge between communities, health care systems, and state health departments. https://www.cdc.gov/chronicdisease/center/community-health-worker-resources.html
CER	**Comparative Effectiveness Research**	Research aimed at evaluating and comparing the implications and outcomes of two or more health care strategies to address a particular medical condition. The goal of comparative effectiveness research is to generate better information about the risks and benefits and costs of different treatment options in order to provide health-care decision makers—including patients, clinicians, purchasers, and policymakers—with up-to-date, evidence-based information about their treatment options to make informed health https://pubmed.ncbi.nlm.nih.gov/22224891/

	Comparators	Two or more options for diagnosis, prevention, treatment, or healthcare delivery that would be available to the patients, caregivers, providers, and/or health systems facing the actual healthcare decision. For PCORI studies, usual care should not be used as a comparator unless it represents a legitimate and coherent clinical option (e.g., a clinical alternative based on guidelines). https://www.pcori.org/glossary
	Comparison	To learn more, researchers compare results from patients in the experimental groups with results from patients in the control groups. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms
	Comparison Group	A group not exposed to a program or treatment. Also referred to as a control group.https://cdc.gov/evaluation/guide/glossary/index.htm
	Compassionate Use	Expanded access, also called "compassionate use," provides a pathway for patients to gain access to investigational drugs, biologics and medical devices for serious diseases or conditions. Investigational drugs and devices have not yet been approved by the FDA and they have not been proven to be safe and effective. Therefore, they may be effective in the treatment of a condition, or they may not. It is important to remember that the drug/biologic/medical device may have unexpected serious side effects and that patients need to consider all the possible risks when seeking access to an investigational medical product. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#C-1
	Comprehensiveness	The Full breadth and depth of coverage on the evaluation issues of interest.https://cdc.gov/evaluation/guide/glossary/index.htm
	Computable Phenotype	Using EHR data to identify persons or populations with a condition or clinical profile. https://starcrn.org/frequently-asked-questions/
	Confidence Level	A statement that the true value of a parameter for a population lays within a specified range of values with a certain level of probability. https://cdc.gov/evaluation/guide/glossary/index.htm
	Confidentiality regarding participants	The practice of maintaining as private all information related to clinical trial participants, including their personal identity and all personal medical information. Results from the study will usually be presented in terms of trends or overall findings and will not mention any specific participants. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#C-1
COI	**Conflict of Interest**	Any association, including a financial or personal association, that has the potential to bias or has the appearance of biasing an individual's decisions in matters related to the Institute or the conduct of activities. https://www.pcori.org/funding-opportunities/what-you-need-know-apply/glossary
CONCERT	**COPD Outcomes-based Network for Clinical Effectiveness & Research Translation**	COPD Outcomes-based Network for Clinical Effectiveness & Research Translation https://jamanetwork.com/journals/jama/article-abstract/186062

COSMOS	**COSMOS**	Epic COSMOS is a repository of patient records from Epic EHR data that is representative of the U.S. population. It can be used to answer practical health questions, inform new clinical interventions, publish research papers, and ultimately drive new standards of care. Participants contribute a subset of HIPAA-approved data from each patient record. COSMOS includes built-in privacy controls and is governed by community stakeholders to ensure that the data is used in the best interest of all participants. https://cosmos.epic.com
	Consultant	Typically, an individual who is not involved with the management of the project, but instead provides general services or subject matter expertise for an hourly fee. https://www.pcori.org/glossary
CMI	**Consumer Medication Information**	Compared to a Medication Guide, a Consumer Medication Information sheet gives broader information on how to use a medicine. CMI sheets are not developed or regulated by FDA. These information sheets are prepared by pharmacies and given out with prescription drugs. CMI sheets are not available on the FDA website. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#C-1
	Control group	The group of participants that receives standard treatment or a placebo. The control group may also be made up of healthy volunteers. Researchers compare results from the control group with results from the experimental group to find and learn from any differences.https://cdc.gov/evaluation/guide/glossary/index.htm
CC	**Coordinating Center**	The CC leads the network's data and engagement activities, connects with outside research partners, and supports the network infrastructure. The coordinating center for our CRN is Duke Clinical Research Institute (DCRI). https://starcrn.org/frequently-asked-questions/
CODA	**COVID-19 and Diabetes study**	
Co-PI	**Co-Principal Investigator**	A PCORI term to identify an individual recognized by the prime institution and the principal investigator (PI) as someone who shares scientific and administrative leadership responsibilities for a project with the PI. The Co-PI is an individual who the PI relies on to contribute substantively to the scientific development and direction of the project in addition to the execution of the project. The Co-PI shares responsibility with the PI for ensuring that milestones are achieved, and contracted deliverables are completed on time. The Co-PI is considered "key personnel " and may be employed by or formally affiliated (through a written agreement) with the prime institution or a collaborating institution. The patient and/or stakeholder partner may be listed as a Co-PI. The designation of a Co-PI does not affect the PI's roles and responsibilities, nor does it imply a Dual PI Award. https://www.pcori.org/glossary
	Cost-Benefit Analysis	An analysis that combines the benefits of a program with the costs of the program. The benefits and costs are transformed into monetary terms.https://cdc.gov/evaluation/guide/glossary/index.htm
	Cost-Effectiveness Analysis	An analysis that combines program costs and effects (impacts). However, the impacts do not have to be transformed into monetary benefits or costs.https://cdc.gov/evaluation/guide/glossary/index.htm

COVID-19	**Coronavirus Disease 2019**	a respiratory disease caused by SARS-CoV-2, a coronavirus discovered in 2019. The virus spreads mainly from person to person through respiratory droplets produced when an infected person coughs, sneezes, or talks. https://www.cdc.gov/dotw/covid-19/index.html
	CRN Central Network Administration	The VUMC administrative and faculty team (Network PI, Network Sr. Project Manager, Network Navigator, and Network Project Manager) that lead centralized operations on behalf of the CRN. https://starcrn.org/frequently-asked-questions/
	CRN Governance Structure	A hybrid of administration and supervision via staff, faculty, and stakeholders that guides our policymaking, project engagement, and decision-making for the network via meetings and workgroups (Leadership Meeting, Operations Meeting, Oversight Council Meeting, Project Manager Meeting, Stakeholder Advisory Council Meeting) to assure responsible conduct of research. https://starcrn.org/frequently-asked-questions/
	Cross-Sectional Data	Data collected at one point in time from various entities.https://cdc.gov/evaluation/guide/glossary/index.htm
	DailyMed	Developed with the National Library of Medicine, DailyMed is a Web site that gives physicians and patients electronic access to FDA-approved drug labels. https://dailymed.nlm.nih.gov/dailymed/
DCA	**Data Collaboration Agreement**	The transfer of data between organizations is common in the research community. When the data is confidential, proprietary, or otherwise considered sensitive, the organization providing the data ("Provider") will often require that the organization receiving the data ("Recipient") enter into a written contract to outline the terms and conditions of the data transfer. https://researchdatamanagement.harvard.edu/data-use-agreements
DCTs	**Decentralized Trials**	Decentralized clinical trials (DCTs) for drugs, biologics and devices, are where some or all the trial-related activities occur at locations other than traditional clinical trial sites.Examples of decentralized elements include obtaining laboratory tests at a local facility rather than a research medical center or conducting a clinical follow-up visit in the trial participant's home using telemedicine. Decentralizing clinical trials will allow some or all trial-related activities to take place at trial participants' homes or other convenient locations, instead of having them visit research sites. www.fda.gov/news-events/press-announcements/fda-takes-additional-steps-advance-decentralized-clinical-trials
DSMB	**Data and Safety Monitoring Board**	An independent committee of experts responsible for reviewing research study data on an ongoing basis to ensure the safety of study subjects and validity and integrity of the data. https://www.pcori.org/glossary
	Data Collection Method	The way facts about a program and its outcomes are amassed. Data collection methods often used in program evaluations include literature search, file review, natural observations, surveys, expert opinion, and case studies.https://cdc.gov/evaluation/guide/glossary/index.htm

	Data Democratization	The process of making information accessible to people and communities, regardless of their technical know-how, so they may work with data comfortably, feel confident talking about it, and ultimately make data-informed decisions.https://www.pcori.org/glossary
DUNS	**Data Universal Numbering System**	A unique identifier assigned to a single business entity. https://www.va.gov/osdbu/docs/factsheetDUNS.pdf
DUA	**Data Use Agreement**	An agreement between institutions for the sharing and use of research data. https://starcrn.org/frequently-asked-questions/
DURSA	**Data Use and Reciprocal Support Agreement**	The Data Use and Reciprocal Support Agreement, a document developed by the NHIN Cooperative DURSA Workgroup in 2009, is a specific agreement signed by every participating National Health Information Network (NHIN). The DURSA can serve as a potential model for any multiparty trust agreement. NewSTEPs: NHIN Data Use and Reciprocal Support Agreement (DURSA).
	Decisional Dilemma	Challenging clinical choices faced by patients, caregivers, clinicians, or health systems about what works best for whom, and under what circumstances. PCORI studies should be designed to support better-informed decisions by generating evidence that improves understanding of the risks and benefits of the available options. https://www.pcori.org/glossary
	De-Identified Data	Data that has been stripped of information such as name and MRN. https://starcrn.org/frequently-asked-questions/
	De-Identified Queries	Counts run on de-identified data to determine the number of patients in the CDM that fit a specific phenotype. https://starcrn.org/frequently-asked-questions/
	Desi	a word sometimes used to describe the people and cultures of the Indian subcontinent (India, Pakistan, Bangladesh) and descendants living abroad. CSUSM-Who is APIDA?.
	Depth	A measurement's degree of accuracy and detail.https://cdc.gov/evaluation/guide/glossary/index.htm
HHS	**U.S. Department of Health & Human Services**	a cabinet-level executive branch department of the U.S. federal government created to protect the health of all Americans and provide essential human services. https://www.hhs.gov/
	Descriptive Statistical Analysis	Numbers and tabulations used to summarize and present quantitative information concisely.https://cdc.gov/evaluation/guide/glossary/index.htm
	Diabetes	A disease in which blood glucose levels are above normal. Most of the food we eat is turned into glucose, or sugar, for our bodies to use for energy.https://cdc.gov/evaluation/guide/glossary/index.htm
	Diffusion or Imitation of Treatment	Respondents in one group get the effect intended for the treatment (program) group. This is a threat to internal validity.https://cdc.gov/evaluation/guide/glossary/index.htm

	Direct Analytic Methods	Methods used to process data to provide evidence on the direct impacts or outcomes of a program.https://cdc.gov/evaluation/guide/glossary/index.htm
	Dissemination (active)	The intentional, active process of identifying target audiences and tailoring communication strategies to increase awareness and understanding of evidence, and to motivate its use in policy, practice, and individual choices. The purpose of dissemination is to spread and sustain knowledge and the associated evidence-based interventions. https://www.pcori.org/glossary
	Dissemination (passive)	Sometimes called research diffusion, is an untargeted dissemination process whereby new evidence is absorbed and acted upon by a small body of highly motivated recipients. https://www.pcori.org/glossary
DEI	**Diversity, Equity, and Inclusion**	**Diversity** is the populations that are nationally underrepresented in the biomedical, clinical, and behavioral and social sciences, which are identified using an evidence-based process. having many different forms, types or ideas; showing variety. **Equity** is the absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g., sex, gender, ethnicity, disability, or sexual orientation). **Inclusion** is A set of behaviors that authentically encourages individuals to feel valued for their unique qualities and experience a sense of belonging and shared power. https://www.ama-assn.org/system/files/ama-assn-equity-guide.pdf
DEI	**Dissemination Evaluation and Implementation**	
	Double-Blind Research Design	A study in which neither the participant nor the researcher knows whether the participant is in the treatment or control group. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#D-1
	Double-Blind, Randomized, Controlled Clinical Trial	This is a clinical trial in which the researchers evenly divide study participants into a group receiving the experimental intervention and a group receiving standard or no treatment. Neither group knows how it has been assigned. This practice reduces the chance for a “placebo effect,” in which a treatment with no active ingredient produces results expected from a treatment with an active ingredient. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#D-1
	Drug Product Recalls	FDA provides information on drug products that have been recalled due to manufacturing problems and/or safety concerns. In addition to information released to the public by a manufacturer using the normal media channels https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#D-1
	Drug Recall	A drug recall is an action taken by a firm to remove a product from the market that FDA considers to be in violation of the law. Recalls are classified as Class I, Class II, or Class III. Class I recalls are the most serious and involve situations where there is a reasonable probability that the use of or exposure to a volatile product, will cause serious adverse health consequences or death. A drug may be recalled due to factors such as problems with packaging, manufacturing, or contamination. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#D-1

	Drug Withdrawal	In rare cases, FDA may need to reassess and change its approval decision on a drug. A conclusion that a drug should no longer be marketed is based on the nature and frequency of the adverse events and how the drug's benefit and risk balance compared with treatment alternatives. When FDA believes that a drug's benefits no longer outweigh its risks, the agency will ask the manufacturer to withdraw the drug. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#D-1
	Drugs@FDA	A resource allows you to search for information about FDA approved brand name and generic drugs and therapeutic biological products. These are proteins derived from living material (such as cells or tissues) used to treat or cure disease. You can search in many ways, including by drug name and active ingredient. https://www.fda.gov/drugs/drug-approvals-and-databases/about-drugsfda
DCRI	**Duke Clinical Research Institute**	The world's largest academic clinical research organization and part of the Duke University School of Medicine. A team of renowned faculty leaders, researchers, and experienced operational experts coming together to follow a singular pursuit: improving outcomes for patients around the world through innovative clinical research. https://dcri.org/
	Durable Power of Attorney	The authority to act for another person in specified or all legal or financial matters. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#D-1
	Early Communication about an ongoing safety review	This type of communication is part of FDA's effort to communicate early with the public when the agency is still evaluating data and has not reached a conclusion. FDA shares information in the interest of informing doctors and patients about the issues that are under review and when FDA experts anticipate completing their review. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#E-1
EFIC	**Exception from informed consent**	Since 1996, federal regulations 21 CFR 50.24 have been available that allow enrollment of critically ill or injured patients into clinical trials using Exception from Informed Consent (EFIC). These regulations are applicable only under narrow clinical circumstances when prospective informed consent is not possible. Examples would include a patient–subject whose critical condition makes it impossible for the patient to give meaningful prospective consent, and it also not feasible to obtain meaningful prospective consent from the patient's Legally Authorized Representative (LAR)..https://med.umn.edu/emergency-med/research/efic#:~:text=Exception%20From%20Informed%20Consent%20(EFIC),-Exception%20From%20Informed
eGFR	**Estimated glomerular rate**	The glomerular filtration rate (GFR) shows how well the kidneys are filtering. An estimated 37 million adults in the United States may have chronic kidney disease (CKD) but nearly 90% are unaware of their condition. When found early, people can take important steps to protect their kidneys. https://www.kidney.org/atoz/content/gfr
EMPI	**Electronic Master Patient Index**	is a valuable reference for basic demographic information and resident activity (i.e. admission and discharge dates) within one source. https://bok.ahima.org/Pages/Long%20Term%20Care%20Guidelines%20TOC/Practice%20Guidelines/Indexes

EHR/EMR	**Electronic Health Record /Electronic Medical Record**	An electronic health record is a repository of electronic information about an individual's health status and health care. EHRs contain much of the same information that is found in a patient's (paper) medical chart, but because the records are digitized, the data can be viewed, and providers (e.g., primary care physicians and specialists) can capture far more extensive information. EHRs may contain administrative and billing data, patient demographics, progress notes, vital signs, medical histories, diagnoses, medications, immunization records, allergies, radiology images, laboratory, and other test results, and much more. https://www.pcori.org/glossary
eMerge	**Electronic Medical Records and Genomics**	a national network organized and funded by the National Human Genome Research Institute (NHGRI) that combines DNA biorepositories with electronic medical record (EMR) systems for large scale, high-throughput genetic research in support of implementing genomic medicine. https://emerge-network.org/
EC	**Engagement Core**	Formerly known as the PCORnet Engagement Coordinating Center (PECC), the PCORnet Engagement Core oversees activities at the national level and to help run activities across PCORnet sites. Aids in the development of strong policies for PCORnet that move the role of stakeholders forward in all PCORnet activities. Led by and engages a diverse range of individuals that represent racial, ethnic, gender, geographic, and other forms of diversity and represents a dynamic group of stakeholders impacted by patient-centered research including families and patients, community groups, local and federal government agencies, clinicians, health systems, and payers. https://www.pcori.org/glossary
EGPA	**Eosinophilic granulomatosis with polyangiitis (EGPA, formerly Churg-Strauss Syndrome)**	Eosinophilic granulomatosis with polyangiitis (EGPA, formerly Churg-Strauss Syndrome) is a disease caused by inflammation (swelling) that occurs in certain types of cells in your blood or in your tissues. Everyone who gets EGPA has a history of asthma and/or allergies. It can affect many of your organs. Almost all people with EGPA have increased numbers of "allergic type" blood cells called eosinophils. Eosinophils are a type of white blood cell that usually make up 5% or less of the total white blood cell count. In EGPA, eosinophils usually make up more than 10% of the total white blood cell count. In addition, most biopsies (tissue samples) contain clusters of cells called "granulomas" that may or may not involve blood vessels. https://my.clevelandclinic.org/health/diseases/7098--eosinophilic-granulomatosis-with-polyangiitis-egpa-formerly-churg-strauss-syndrome
EPC	**Evidence-Based Practice Center**	The EPCs produce evidence reports on medications, devices, and other health care services for the EHC Program with the goal of helping consumers, health care professionals, and policymakers make informed and evidence-based health care decisions. https://effectivehealthcare.ahrq.gov/about/epc
EPIC	**EPIC**	Epic Systems Corporation, or Epic, is an American privately held healthcare software company. Hospitals that use its software held medical records of 78% of patients in the United States and over 3% of patients worldwide in 2022. https://www.epic.com/

ePRO	**Electronic Patient Reported Outcome**	Report of the status of a patient's health condition or health behavior. comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else recorded on an electronic device during a clinical trial. https://www.pcori.org/document/users-guide-integrating-patient-reported-outcomes-electronic-health-records
ETL	**Extract, Transform, Load**	used to combine data for long-term use into data warehouses, data hub or data lake structures.
EIN	**Employer Identification Number**	The Federal Tax Identification Number used to identify a business entity. https://www.pcori.org/glossary
	Engagement in Research	The meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. https://www.pcori.org/glossary
	Engagement Rubric	A PCORI resource intended to provide guidance regarding engagement in the conduct of research to those planning or conducting research, merit reviewers, awardees, engagement/program officers (for creating milestones and monitoring projects), and interested patients, caregivers, patient/caregiver organizations, and other stakeholders. https://www.pcori.org/resources/engagement-rubric
ETL	**Extract transfer link**	Extract Transfer Link of medical record data
	Evaluation Design	The logical model or conceptual framework used to arrive at conclusions about outcomes.https://cdc.gov/evaluation/guide/glossary/index.htm
	Evaluation Plan	A written document describing the overall approach or design that will be used to guide an evaluation. It includes what will be done, how it will be done, who will do it, when it will be done, why the evaluation is being conducted, and how the findings will likely be used.https://cdc.gov/evaluation/guide/glossary/index.htm
	Evaluation Strategy	The method used to gather evidence about one or more outcomes of a program. An evaluation strategy is made up of an evaluation design, a data collection method, and an analysis technique.https://cdc.gov/evaluation/guide/glossary/index.htm
	Evidence for Engagement	Manuscripts that include a formal evaluation of engagement within the context of a health research study, or a study with the primary objective to evaluate or synthesize engagement methods/impacts in health research. https://www.pcori.org/glossary
	Evidence Updates	These materials present information from recent PCORI studies or from systematic reviews that summarize evidence. Created in collaboration with patient organizations, clinicians, and others with an interest in the findings, these materials bring timely and relevant information to audiences who can benefit from knowing and using the information. https://www.pcori.org/glossary
	Ex Ante Cost-Benefit or Cost-Effectiveness Analysis	A cost-benefit or cost-effectiveness analysis that does not estimate the actual benefits and costs of a program but that uses hypothesized before-the-fact costs and benefits. This type of analysis is used for planning purposes rather than for evaluation.https://cdc.gov/evaluation/guide/glossary/index.htm

	Ex Post Cost-Benefit or Cost-Effectiveness Analysis	A cost-benefit or cost-effectiveness analysis that takes place after a program has been in operation for some time and that is used to assess actual costs and actual benefits.https://cdc.gov/evaluation/guide/glossary/index.htm
	Example of Engagement in Health Research	Manuscripts with a primary objective of reporting on a health research study that engaged partners in at least one phase of the research and describe at least one impact of engagement on their work.
	Executive Summary	A nontechnical summary statement designed to provide a quick overview of the full-length report on which it is based.https://cdc.gov/evaluation/guide/glossary/index.htm
	Expanded Access	Also called “compassionate use,” provides a pathway for patients to gain access to investigational drugs, biologics and medical devices for serious diseases or conditions. Investigational drugs and devices have not yet been approved by the FDA and they have not been proven to be safe and effective. Therefore, they may be effective in the treatment of a condition, or they may not. It is important to remember that the drug/biologic/medical device may have unexpected serious side effects and that patients need to consider all the possible risks when seeking access to an investigational medical product. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#E-1
	Experiment	A study done to answer a question. Other words to describe an experiment are “research,” “study,” and “protocol.” https://www.khanacademy.org/math/statistics-probability/designing-studies/types-studies-experimental-observational/a/observational-studies-and-experiments
	Experimental (or randomized) Designs	Designs that try to ensure the initial equivalence of one or more control groups to a treatment group by administratively creating the groups through random assignment, thereby ensuring their mathematical equivalence. Examples of experimental or randomized designs are randomized block designs, Latin square designs, fractional designs, and the Solomon four-group.https://cdc.gov/evaluation/guide/glossary/index.htm
	Experimental Group	The group of participants in a study that receive the experimental or study intervention (such as medication or psychotherapy). https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#E-1
	Expert Opinion	A data collection method that involves using the perceptions and knowledge of experts in functional areas as indicators of program outcome.https://cdc.gov/evaluation/guide/glossary/index.htm
	External Validity	The ability to generalize conclusions about a program to future or different conditions. Threats to external validity include selection and program interaction, setting and program interaction, and history and program interaction.https://cdc.gov/evaluation/guide/glossary/index.htm
FDA	**Food and Drug Administration**	a U.S. federal agency of the Department of Health and Human Services responsible for protecting and promoting public health through the control and supervision of food safety, tobacco products, dietary supplements, prescription and over-the-counter pharmaceutical drugs (medications),

		vaccines, biopharmaceuticals, blood transfusions, medical devices, electromagnetic radiation emitting devices (ERED), cosmetics, animal foods & feed[3] and veterinary products. https://www.fda.gov/
	FDA Adverse Reporting System	A computerized database containing reports of adverse events. It supports FDA's post-market safety surveillance program for all approved drugs and therapeutic biologics. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#F-1
	FDASIA Section 907	Directed FDA to report on the extent to which demographic subgroups (sex, age, race and ethnicity) participate in clinical trials in marketing applications for drugs, biologics, and devices. This report provided an important opportunity to take a closer look at the inclusion and analysis of demographic subgroups. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#F-1
FHIR	**Fast Healthcare Interoperability Resources**	Standard defines how healthcare information can be exchanged between different computer systems regardless of how it is stored in those systems. https://www.healthit.gov/sites/default/files/2019-08/ONCFHIRFSWhatIsFHIR.pdf
FDP	**Federal Demonstration Project**	The FDP is a program convened by the Government-University-Industry Research Roundtable of the National Academies. Its purpose is to reduce the administrative burdens associated with research grants and contracts.https://thefdp.org/
	Federal Register	Abbreviated FR or sometimes Fed. Reg., is the official journal of the federal government of the United States that contains most routine publications and public notices of government agencies. It is a daily (except federal holidays) publication. The Federal Register is compiled by the Office of the Federal Re gister (within the National Archives and Records Administration) and is printed by the Government Printing Office. The final rules promulgated by a federal agency and published in the Federal Register are ultimately reorganized by topic or subject matter and codified in the Code of Federal Regulations (CFR), which is updated annually. There are no copyright restrictions on the Federal Register; as a work of the U.S. government, it is in the public domain.[1] Citations from the Federal Register are [volume] FR [page number] ([date]), e.g., 65 FR 741 (Jan. 6, 2000). https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#F-1
	File Review	A data collection method involving a review of program files. There are usually two types of program files: general program files and files on individual projects, clients, or participants.https://cdc.gov/evaluation/guide/glossary/index.htm
	Final Research Report	The Final Research Report is a comprehensive account of all the work done in this study and has been peer reviewed by research experts and patients with lived experience. It includes details on the investigators' work with patients and other stakeholders throughout the study process. It also includes important information about what did not work in the planned research and lessons investigators learned that will inform future research. https://www.pcori.org/glossary

FO	**Financial Official**	The individual designated by the recipient organization who is responsible for the proper accounting of contract funds and the submission of payment details. The FO is responsible for completing and certifying the required yearly expenditure reports. https://www.pcori.org/glossary
FG	**Focus Group**	A group of people selected for their relevance to an evaluation that is engaged by a trained facilitator in a series of discussions designed for sharing insights, ideas, and observations on a topic of concern.https://cdc.gov/evaluation/guide/glossary/index.htm
	Form FDA 3926	Used by physicians when submitting requests for expanded access to investigational drugs, including emergency requests. This form is designed specifically for single patient requests only. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#F-1
	Fringe Benefits	A form of pay for the performance of services. Fringe benefits commonly include health insurance, group term life coverage, and nonwage compensation. https://www.pcori.org/funding-opportunities/what-you-need-know-apply/glossary
	Front Door	The main access point for potential investigators, patient groups, health systems, and funders to reach the PCORnet infrastructure. https://starcrn.org/frequently-asked-questions/
GDPR	**General Data Protection Regulation**	an EU-wide law that protects Europeans in regard to the processing of their personal data, as well as laying down the rules relating to the free movement of personal data. https://gdpr-info.eu/
GCP	**Good Clinical Practice**	an international ethical and scientific quality standard for the design, conduct, performance, monitoring, auditing, recording, analyses and reporting of clinical trials. It also serves to protect the rights, integrity and confidentiality of trial subjects. https://www.fda.gov/about-fda/center-drug-evaluation-and-research-cder/good-clinical-practice
	Governance	The system of administration and supervision through which the CRN is managed, participants and staff are protected, and accountability is assured. A multi-stakeholder process that involves all participants in the structure to strive for consensus-based decision-making and operating in an open, transparent, and accountable manner. https://starcrn.org/frequently-asked-questions/
	Greater-Than Request	A request for budget and/or time that exceeds the total award amount and/or maximum project period specified in the funding announcement. https://www.pcori.org/glossary
GRF	**Glomerular filtration rate (GFR)**	The glomerular filtration rate (GFR) shows how well the kidneys are filtering blood by removing waste and extra water to make urine. https://www.kidney.org/atoz/content/gfr
GLP	**Glucagon-like peptide 1**	Drugs used to treat diabetes and obesity. Common trade names include Trulicity, ozempic.
HCAHPS	**HCAHPS: Patients' Perspectives of Care Survey**	The HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) survey is the first national, standardized, publicly reported survey of patients' perspectives of hospital care. HCAHPS (pronounced "H-caps"), also known as the CAHPS Hospital Survey, is a survey instrument and data collection methodology for measuring patients' perceptions of their hospital experience. While many hospitals have collected information on patient satisfaction for their own internal use,

		until HCAHPS there was no national standard for collecting and publicly reporting information about patient experience of care that allowed valid comparisons to be made across hospitals locally, regionally and nationally https://www.hhs.gov/guidance/document/hcahps-patients-perspectives-care-survey-0
	Health Equity	The elimination of systemic obstacles and the creation of opportunities for all to be healthy. https://www.ama-assn.org/system/files/ama-assn-equity-guide.pdf
HES		Hypereosinophilic syndrome
	Healthy volunteer	In a clinical study, a person who does not have the disorder or disease being studied. Results from healthy controls are compared to results from the group being studied. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
HIPAA	**Health Insurance Portability and Accountability Act**	a federal law that required the creation of national standards to protect sensitive patient health information from being disclosed without the patient's consent or knowledge. https://www.cdc.gov/phlp/publications/topic/hipaa.html
	History	Events outside the program that affect the responses of those involved in the program.https://cdc.gov/evaluation/guide/glossary/index.htm
	History and Program Interaction	The conditions under which the program took place are not representative of future conditions. This is a threat to external validity.https://cdc.gov/evaluation/guide/glossary/index.htm
HSP	**Human Subjects Protection**	a collective term for the federal, state, and university policies, procedures, and ethical considerations that protect the rights and welfare of human beings who participate in research as the subjects of that research. https://www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html
HSSI	**The Health Systems Implementation Initiative (HSII)**	is a new multiyear PCORI initiative to advance the uptake of practice-changing comparative clinical effectiveness research results in care delivery settings. HSII is intended to facilitate lasting change within participating systems and lay groundwork for broader adoption of evidence-based practices. Through HSII, PCORI will provide funding to HSII Participant healthcare delivery systems to undertake implementation projects to actively advance the adoption of new evidence. These projects will have the goal of promoting the uptake of specific PCORI-funded evidence in practice. PCORI's Board of Governors has committed an initial investment of up to $50 million to support implementation under HSII. HSII is intended to facilitate lasting change within participating systems and lay groundwork for broader adoption of evidence-based practices. https://www.pcori.org/impact/putting-evidence-work/health-systems-implementation-initiative

i2b2	**Informatics for Integrating Biology and the Bedside**	The i2b2 tranSMART Foundation is a member-driven non-profit foundation developing an open-source / open-data community around the i2b2, tranSMART and OpenBEL translational research platforms. https://www.i2b2.org/
ICD	**International Classification of Disease Codes**	Codes that allow the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or regions and at different times, which ensures reusability of recorded data for the different use cases beyond health statistics, including decision support, resource allocation, reimbursement, guidelines and more. https://www.who.int/standards/classifications/classification-of-diseases
ICD	**Implantable Cardioverter Defibrillators**	An implantable cardioverter-defibrillator (ICD) is a small battery-powered device placed in the chest to detect and stop irregular heartbeats (arrhythmias). https://www.mayoclinic.org/tests-procedures/implantable-cardioverter-defibrillators/about/pac-20384692
IDD	**Intellectual or Developmental Disability**	differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems. https://www.nichd.nih.gov/health/topics/idds/conditioninfo
	Ideal Evaluation Design	The conceptual comparison of two or more situations that are identical except that in one case the program is operational. Only one group (the treatment group) receives the program; the other groups (the control groups) are subject to all pertinent influences except for the operation of the program, in the same fashion as the treatment group. Outcomes are measured in the same way for both groups and any differences can be attributed to the program.https://cdc.gov/evaluation/guide/glossary/index.htm
	Implementation	The deliberate, iterative process of integrating evidence into policy and practice through adapting evidence to different contexts and facilitating behavior change and decision making based on evidence across individuals, communities, and healthcare systems. https://www.pcori.org/glossary
	Implicit Design	A design with no formal control group and where measurement is made after exposure to the program. https://cdc.gov/evaluation/guide/glossary/index.htm
	In vitro	In glass, as in a test tube. An in vitro test is one that is done in glass or plastic vessels in the laboratory. In vitro is the opposite of in vivo. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#I-1
	In vivo	In the living organism. For example, an experiment that is done in vivo is done in the body of a living organism. In vivo is the opposite of in vitro. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#I-1
	Inclusion/Exclusion Criteria	Inclusion/Exclusion Criteria are factors that allow someone to participate in a clinical trial are *inclusion criteria*. Those that exclude or not allow participation are *exclusion criteria*. These factors may include a person's illness, health history, past treatment, age, sex, or where he or she lives. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms

	Indicator	A specific, observable, and measurable characteristic or change that shows the progress a program is making toward achieving a specified outcome.https://cdc.gov/evaluation/guide/glossary/index.htm
	Indirect Costs	Costs not directly accountable to the project. Indirect costs include taxes, administration, personnel (not directly related to the project), and security costs. https://www.pcori.org/glossary
	Inferential Statistical Analysis	Statistical analysis using models to confirm relationships among variables of interest or to generalize findings to an overall population. https://cdc.gov/evaluation/guide/glossary/index.htm
	Informal Conversational Interview	An interviewing technique that relies on the natural flow of a conversation to generate spontaneous questions, often as part of an ongoing observation of the activities of a program. https://cdc.gov/evaluation/guide/glossary/index.htm
ISO	**Information Security Office**	Officer will be responsible for overseeing information security, cybersecurity and Information Technology risk management programs based on industry-accepted information security and risk management frameworks. https://www.techtarget.com/searchsecurity/definition/CISO-chief-information-security-officer
IC	**Informed Consent**	Informed consent explains risks and potential benefits about a clinical trial before someone decides whether to participate. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#I-1
	Inpatient	A person who is hospitalized for at least one night to receive treatment or participate in a study. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#I-1
	Inpatient Costs	Costs incurred for patient study participants who are formally admitted to a hospital on doctor's orders https://www.pcori.org/glossary
	Inputs	Resources that go into a program in order to mount the activities successfully https://cdc.gov/evaluation/guide/glossary/index.htm
IRB	**Institutional Review Board**	A group that follows federal regulations, state laws, and institutional policy to review, monitor, and approve research to protect the ethical rights and privacy of the subjects involved. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#I-1
	Instrumentation	The effect of changing measuring instruments from one measurement to another, as when different interviewers are used. This is a threat to internal validity https://cdc.gov/evaluation/guide/glossary/index.htm
	Interaction Effect	The joint net effect of two (or more) variables affecting the outcome of a quasi-experiment https://cdc.gov/evaluation/guide/glossary/index.htm

	Internal Validity	The ability to assert that a program has caused measured results (to a certain degree), in the face of plausible potential alternative explanations. The most common threats to internal validity are history, maturation, mortality, selection bias, regression artifacts, diffusion, and imitation of treatment and testing. https://cdc.gov/evaluation/guide/glossary/index.htm
	Interventional Research	A clinical study in which participants are assigned to receive one or more intervention (or no interventions) so that researchers can evaluate the effects of the interventions on biomedical or health-related outcomes. https://starcrn.org/frequently-asked-questions/
	Interview Guide	A list of issues or questions to be raised during an interview. https://cdc.gov/evaluation/guide/glossary/index.htm
	Interviewer Bias	The influence of the interviewer on the interviewee. This may result from several factors, including the physical and psychological characteristics of the interviewer, which may affect the interviewees and cause differential responses among them. https://cdc.gov/evaluation/guide/glossary/index.htm
IIT	**Investigator Initiated Trial**	a study with scientific and medical merit developed, initiated, and sponsored by an independent investigator, researcher, a research group, or institution https://ispe.org/publications/papers/investigator-initiated-trials-considerations-guidance-perspective-clinical-trial-supplies-gmp
IND	**Investigational New Drug**	A substance that has been tested in the laboratory and has been approved by the U.S. Food and Drug Administration (FDA) for testing in people. Clinical trials test how well investigational new drugs work and whether they are safe to use. An investigational new drug may be approved by the FDA for use in one disease or condition but still be considered investigational in other diseases or conditions. Also called experimental drug, IND, investigational agent, and investigational drug. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#I-1
	Key Personnel	Individuals who contribute to the scientific development or execution of the project in a substantive and measurable way. The contribution is independent of financial compensation. https://www.pcori.org/glossary
KSEC	**Kidney Stone Engagement Core**	Composed of individuals who are dedicated to enhancing the patient voice in kidney stone research. They are patients with kidney stones, caregivers who are for individuals with kidney stones, and advocates for patients with a diverse array of kidney stone experiences.They are researchers and clinicians who are dedicated to high-impact research in kidney stone disease. kidneystonecentral.org/who-we-are/
	Joint Commission	The mission of The Joint Commission is to continuously improve health care for the public, in collaboration with other stakeholders, by evaluating health care organizations and inspiring them to excel in providing safe and effective care of the highest quality and value. https://www.jointcommission.org/
LDS	**Limited Data Set**	'A “limited data set” is a limited set of identifiable patient information as defined in the Privacy Regulations issued under the Health Insurance Portability and Accountability Act, better known as “HIPAA”. A “limited data set” of information may be disclosed to an outside party without a patient’s

		authorization if certain conditions are met. First, the purpose of the disclosure may only be for research, public health or health care operations. https://www.hopkinsmedicine.org/institutional-review-board/hipaa-research/limited-data-set
	Leadership Meeting	A weekly meeting consisting of CRN Central Administrative Staff, STAR Site Teams, and voting members of the STAR Leadership Team (10 voting members). https://starcrn.org/frequently-asked-questions/
LOI	**Letter of Intent or Letter of Inquiry**	A letter notifying an agency that an organization/institution intends to submit an application for a funding announcement. https://www.pcori.org/glossary
	Letters of Collaboration	Signed letters from each collaborating individual or organization that will demonstrate that the PI has the support or resources necessary for the proposed work. Letters of support from patient and stakeholder partners should clearly describe the origin of the study topic and the role of the patient partners in defining the question, outcomes, comparators, goals and outcomes, etc. Letters from the partners or partnering organizations affirming support to disseminate and implement research findings that are germane and warranted for implementation are also highly encouraged.https://www.pcori.org/glossary
	Letters of Organizational Support	Letters of support signed by the Department Chair or appropriate organizational official, confirming the institutional support of the proposed project, space to conduct the research, equipment, and other resources available for the project, including staff. A letter from the leadership of your department or organization affirming support to disseminate research findings that are appropriate and warranted for implementation may also be included. https://www.pcori.org/glossary
	Limited Competition	The process by which only certain groups may apply for an award, such as only networks or teams that have a completed a project previously for that funding agency. https://www.pcori.org/glossary
	List Sampling	Usually in reference to telephone interviewing, a technique used to select a sample. The interviewer starts with a sampling frame containing telephone numbers, selects a unit from the frame, and conducts an interview over the telephone either with a specific person at the number or with anyone at the number. https://cdc.gov/evaluation/guide/glossary/index.htm
	Literature Search	A data collection method that involves an identification and examination of research reports, published papers, and books .https://cdc.gov/evaluation/guide/glossary/index.htm
	Logic Model	A systematic and visual way to present the perceived relationships among the resources you have to operate the program, the activities you plan to do, and the changes or results you hope to achieve. https://cdc.gov/evaluation/guide/glossary/index.htm
LOINC	**Logical Observation Identifiers Names and Codes**	Logical Observation Identifiers Names and Codes (Logical Observation Identifiers Names and Codes) is a common language (a set of identifiers, names, and codes) for identifying health measurements, observations, and documents, including laboratory tests, clinical measures, and other data in the electronic health record. https://loinc.org/about/

	Longitudinal Data	Data collected over a period of time, sometimes involving a stream of data for particular persons or entities over time. https://cdc.gov/evaluation/guide/glossary/index.htm
MACE		Major Adverse Cardiovascular Events
	Macro-Economic Model	A model of the interactions between the goods, labor, and assets markets of an economy. The model is concerned with the level of outputs and prices based on the interactions between aggregate demand and supply. https://cdc.gov/evaluation/guide/glossary/index.htm
	Main Effects	The separate independent effects of each experimental variable. https://cdc.gov/evaluation/guide/glossary/index.htm
	Matching	Dividing the population into "blocks" in terms of one or more variables (other than the program) that are expected to have an influence on the impact of the program. https://cdc.gov/evaluation/guide/glossary/index.htm
	Maturation	Changes in the outcomes that are a consequence of time rather than of the program, such as participant aging. This is a threat to internal validity .https://cdc.gov/evaluation/guide/glossary/index.htm
	Maximum Acceptable Risk	The greatest increase in probability or magnitude of a harm that a patient would accept for a given benefit. https://neac.health.govt.nz/national-ethical-standards/part-two/8-research-benefits-and-harms/
	Measurement Validity	A measurement is valid to the extent that it represents what it is intended and presumed to represent. Valid measures have no systematic bias. https://cdc.gov/evaluation/guide/glossary/index.htm
	Measuring Devices or Instruments	Devices that are used to collect data (such as questionnaires, interview guidelines, and observation record forms). https://cdc.gov/evaluation/guide/glossary/index.htm
	Medication Guides	Paper hand-outs/pamphlets that are required to be given to patients with certain medications by the pharmacist. Medication Guides communicate risk information that is specific to particular drugs and drug classes, and they contain FDA-approved information that can help patients avoid serious adverse events. https://www.fda.gov/drugs/drug-safety-and-availability/medication-guides
	MedWatch	MedWatch is FDA's safety information and adverse event reporting program. It provides important and timely medical product information to healthcare professionals, including information on prescription and over- the-counter drugs, biologics, medical devices, and special nutritional products. Healthcare professionals and consumers can also report serious problems they suspect are related to certain FDA-regulated products. https://www.fda.gov/safety/medwatch-fda-safety-information-and-adverse-event-reporting-program
METRC	**Meharry Clinical and Translational Research Center**	Seeks to understand diseases and health disorders that disproportionately impact minorities so that strategies for cure can be implemented. The center cultivates minority researchers by funding their projects, and building an infrastructure of laboratories, training, and support staff to establish a national model for clinical and translational health disparities research.

		https://www.meharryresearch.org/research/innovation-centers/clinical-translational-research/clinical-translational-research-core/
	Merit Review	A review of the scientific and technical merit of applications for funding. Merit review consists of both online and in-person reviews by qualified reviewers who read, score, and provide feedback on the applications. https://www.pcori.org/glossary
	Merit Review Officer	A scientist who presides over a merit review panel and is responsible for coordinating and reporting the discussion of each application assigned to it. The MRO serves as an intermediary between the applicant and reviewers and prepares summary statements for all applications reviewed. https://www.pcori.org/glossary
	Micro-Economic Model	A model of the economic behavior of individual buyers and sellers, in a specific market and set of circumstances. https://cdc.gov/evaluation/guide/glossary/index.htm
	Minimal Risk	The probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#M-1
	Minimum Required Benefit	The smallest increase in probability or magnitude of a benefit that a patient would require to offset a given risk. https://irb.unm.edu/library/documents/guidance/assessing-and-minimizing-risk-in-human-research.pdf
	Minoritized	to make (a person or group) subordinate in status, mistreated, discriminated, and given less access to resources by a numerically larger group by means out of their own control
	Monetary Policy	Government action that influences the money supply and interest rates. May also take the form of a program.https://cdc.gov/evaluation/guide/glossary/index.htm
MMM	**Maternal Morbidity and Mortality**	**Maternal morbidity** describes any short- or long-term health problems that result from being pregnant and giving birth. **Maternal mortality** refers to the death of a woman from complications of pregnancy or childbirth that occur during the pregnancy or within 6 weeks after the pregnancy ends. https://www.nichd.nih.gov/health/topics/factsheets/maternal-morbidity-mortality
	Mortality	Treatment (or control) group participants dropping out of the program. It can undermine the comparability of the treatment and control groups and is a threat to internal validity. https://cdc.gov/evaluation/guide/glossary/index.htm
	Multiples Lines of Evidence	The use of several independent evaluation strategies to address the same evaluation issue, relying on different data sources, on different analytical methods, or on both. https://cdc.gov/evaluation/guide/glossary/index.htm

MPI	**Multiple Principal Investigators**	An important opportunity for investigators seeking support for projects or activities that require a team science approach that involve multiple principal investigators. https://grants.nih.gov/grants/multi_pi/overview.htm
NCATS	**National Center for Advancing Translational Sciences**	A function of the NIH, NCATS aims to transform the translational science process so that new treatments and cures for disease can be delivered to patients faster. Translational sciences comprise the process of turning observations in the laboratory and clinic into effective interventions that improve the health of individuals and the public — from diagnostics and therapeutics to medical procedures and behavioral changes. https://ncats.nih.gov/research/research-activities/ctsa
NCI	**National Cancer Institute**	The NCI is part of the National Institutes of Health (NIH), which is one of 11 agencies that compose the Department of Health and Human Services (HHS). The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. https://www.cancer.gov/
NCR	**Network Collaboration Request**	Front door document to engage with networks for study collaboration. Initiated by the study team. https://starcrn.org/
NDA	**Non-Disclosure Agreement**	a legal contract between at least two parties to share confidential material, knowledge, or information. (aka: confidentiality agreement) https://nondisclosureagreement.com/wp-content/uploads/2020/11/Basic-Non-Disclosure-Agreement.pdf
NHANES	**National Health and Nutrition Examination Survey**	National Health and Nutrition Examination Survey (NHANES) is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews and physical examinations. NHANES is a major program of the National Center for Health Statistics (NCHS). NCHS is part of the Centers for Disease Control and Prevention (CDC) and has the responsibility for producing vital and health statistics for the Nation.https://www.cdc.gov/nchs/nhanes/index.htm
NIH	**National Institutes of Health**	Part of the U.S. Department of Health and Human Services, NIH is the primary Federal agency for conducting and supporting medical research. NIH scientists investigate ways to prevent disease as well as the causes, treatments, and even cures for common and rare diseases. Composed of 27 Institutes and Centers, NIH provides leadership and financial support to researchers in every state and throughout the world. https://www.nih.gov/
NIMHD	**National Institutes on Minority Health and Health Disparities**	NIH institute that leads scientific research to improve minority health and eliminate health disparities. https://www.nimhd.nih.gov/
NLM	**National Library of Medicine**	The world's largest biomedical library, the National Library of Medicine (NLM) maintains and makes available a vast print collection and produces electronic information resources on a wide range of topics that are searched billions of times each year by millions of people around the globe. It also supports and conducts research, development, and training in biomedical informatics and health information technology. In addition, the library coordinates a 6,000-member National Network of

		Libraries of Medicine that promotes and provides access to health information in communities across the United States. https://www.nlm.nih.gov/
NLP	**Natural Language Processing**	Branch of linguistics, computer science, and artificial intelligence concerned with the interactions between computers and human language, in particular how to program computers to process and understand text and spoken words in much the same way human beings can
	Natural Observation	A data collection method that involves on-site visits to locations where a program is operating. It directly assesses the setting of a program, its activities, and individuals who participate in the activities. https://cdc.gov/evaluation/guide/glossary/index.htm
	New Drug Approval Process	After the animal testing stage, FDA decides whether it is reasonably safe for the company to move forward with clinical trials—studies that evaluate the safety and effectiveness of a drug in healthy people and in patients. The drug company submits the results of such studies to FDA for review. The agency conducts a thorough review of the safety and effectiveness data and considers how the benefits compare to the risks when making a decision of whether or not to approve a drug. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#N-1
NCATS	**National Center for Advancing Translational Science**	The National Center for Advancing Translational Sciences (NCATS) — one of 27 Institutes and Centers at the National Institutes of Health (NIH) — was established to transform the translational process so that new treatments and cures for disease can be delivered to patients faster. https://ncats.nih.gov/
NOGA	**Notice of Grant Award**	The Notice of Award (NoA) is the official grant award document notifying the recipient and others that an award has been made. The NoA contains all terms and conditions of the grant award and provides the support documentation for recording the obligation of federal funds in the agency's accounting system.https://www.era.nih.gov/recipients/view-notice-of-award.htm
	Nonprescription Drug Label ("Drug Facts")	For an over the counter (OTC), or nonprescription medicine, information printed on the medication bottle or package under the heading Drug Facts is important for taking care of yourself and your family. The Drug Facts tell you what a medicine is supposed to do, who should or should not take it, and how to use it. Safety information and instructions for use are displayed in a uniform and easy-to-read format.https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#N-1
	Non-Probability Sampling	When the units of a sample are chosen so that each unit in the population does not have a calculable non-zero probability of being selected in the sample. https://cdc.gov/evaluation/guide/glossary/index.htm
	Non-Response	A situation in which information from sampling units is unavailable. https://cdc.gov/evaluation/guide/glossary/index.htm
	Non-Response Bias	Potential skewing because of non-response. The answers from sampling units that do produce information may differ on items of interest from the answers from the sampling units that do not reply. https://cdc.gov/evaluation/guide/glossary/index.htm

	Non-Sampling Error	The errors, other than those attributable to sampling, that arise during the course of almost all survey activities (even a complete census), such as respondents' different interpretation of questions, mistakes in processing results, or errors in the sampling frame. https://cdc.gov/evaluation/guide/glossary/index.htm
	NORC	NORC at the University of Chicago is an independent research institution that delivers reliable data and rigorous analysis. https://www.norc.org/About/Pages/default.aspx The recommended first reference is "the nonpartisan and objective research organization NORC at the University of Chicago," with subsequent references simply NORC. If it is spoken, we say "Norc" as one word. Founded and incorporated in 1941 as the National Opinion Research Center and this remains the legal name. "NORC" is the externally facing, to-do-business (TDB) name, not an acronym (similar to IBM, AT&T, RAND, and GEICO). We use NORC at the University of Chicago to emphasize our close affiliation with the University.
	Objective Data	Observations that do not involve personal feelings and are based on observable facts. Objective data can be measured quantitatively or qualitatively. https://cdc.gov/evaluation/guide/glossary/index.htm
	Objectivity	Evidence and conclusions that can be verified by someone other than the original authors. https://cdc.gov/evaluation/guide/glossary/index.htm
	Observational Research	A clinical study in which participants identified as belonging to study groups are assessed for biomedical or health outcomes. https://starcrn.org/frequently-asked-questions/
	Off Label Use	Also called unapproved use of an approved product, is when your healthcare provider uses an FDA-approved medical product for a use that has not been studied yet. https://www.fda.gov/patients/learn-about-expanded-access-and-other-treatment-options/understanding-unapproved-use-approved-drugs-label
OHRP	**Office for Human Research Protections**	provides leadership in the protection of the rights, welfare, and wellbeing of human subjects involved in research conducted or supported by the U.S. Department of Health and Human Services (HHS). OHRP is part of the Office of the Assistant Secretary for Health in the Office of the Secretary of HHS.OHRP provides clarification and guidance, develops educational programs and materials, maintains regulatory oversight, and provides advice on ethical and regulatory issues in biomedical and behavioral research. OHRP also supports the Secretary's Advisory Committee on Human Research Protections (SACHRP), which advises the HHS Secretary on issues related to protecting human subjects in research. Department of Health & Human Services: OHRP.
OHE	**Office of Health Equity (VUMC)**	Serves as an institutional home for nurturing and catalyzing educational, research, clinical, and operational initiatives, and partnerships to address and prevent health inequities. https://www.vumc.org/healthequity/welcome-office-health-equity

OMH	**Office of Minority Health (HHS)**	Established in 2010; OMH serves as the principal advisor to the Commissioner on minority health and health disparities. The Office provides leadership and direction in identifying agency actions that can help reduce health disparities, including the coordination of efforts across the Agency. https://www.minorityhealth.hhs.gov/
OMOP	**Observational Medical Outcome Partnership**	The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) is an open community data standard, designed to standardize the structure and content of observational data and to enable efficient analyses that can produce reliable evidence. https://www.ohdsi.org/data-standardization/
	Operations Meeting	A quarterly meeting attended by STAR CRN Site Teams and past/present STAR CRN Project PIs. Provides an update on STAR CRN operations and metrics, while also providing a venue for STAR CRN Project PIs to present project results. https://starcrn.org/frequently-asked-questions/
	Order Bias	A skewing of results caused by the order in which questions are placed in a survey. https://cdc.gov/evaluation/guide/glossary/index.htm
	Outcome Effectiveness Issues	A class of evaluation issues concerned with the achievement of a program's objectives and the other impacts and effects of the program, intended or unintended. https://cdc.gov/evaluation/guide/glossary/index.htm
	Outcome Evaluation	The systematic collection of information to assess the impact of a program, present conclusions about the merit or worth of a program and make recommendations about future program direction or improvement. https://cdc.gov/evaluation/guide/glossary/index.htm
	Outcomes	Outcomes (also called events or endpoints) are variables that are monitored during a study to document the impact that a given intervention or exposure has on the health of a given population. Typical examples of outcomes are cure, clinical worsening, and mortality. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5790671/#:~:text=DEFINITIONS,%2C%20clinical%20worsening%2C%20and%20mortality
	Outpatient	A person who receives treatment or participates in a study but is not hospitalized overnight. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#O-1
	Outpatient Costs	Costs incurred for patient care when the patient is not formally admitted to a hospital. https://www.pcori.org/glossary
	Outputs	The direct products of program activities; immediate measures of what the program did. https://cdc.gov/evaluation/guide/glossary/index.htm
	Oversight Council Meeting	A twice-yearly meeting designed to provide high-level STAR CRN information to executive leadership at STAR CRN Sites to encourage continued growth and discuss future direction. https://starcrn.org/frequently-asked-questions/

P30	**Center Core Grant**	National Institute of Health (NIH) Center Core Grants (P30) that support shared resources and facilities for use by multiple investigators to enhance multidisciplinary approaches and collaborative research efforts focused on a common research problem or goal. The core grant is utilized by independently funded research projects. https://www.niddk.nih.gov/research-funding/process/apply/funding-mechanisms/p30
PCORI	**Patient Centered Outcomes Research Institute**	an independent, nonprofit research organization that seeks to empower patients and others with actionable information about their health and healthcare choices. We fund comparative clinical effectiveness research (CER), which compares two or more medical treatments, services, or health practices to help patients and other stakeholders make better informed decisions. https://www.pcori.org/glossary
PCoR	**Patient-Centered Outcomes Research**	Research that helps people and their caregivers communicate and make informed healthcare decisions, while allowing their voices to be heard in assessing the value of healthcare options. This research answers patient-centered questions. https://www.pcori.org/glossary
	Patient Engagement	Involvement of patients and other stakeholders throughout the planning, conduct, and dissemination of the proposed projects. https://www.pcori.org/glossary
PFAC	**Patient Family Advisory Council**	The Institute for Patient- and Family-Centered Care (IPFCC), a non-profit organization founded in 1992, takes pride in providing essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support.https://www.ipfcc.org/bestpractices/sustainable-partnerships/engaging/effective-pfacs.html
	Patient Investigator	Patients or other stakeholders involved in the investigation of research who have a role in guiding the aims of the study. https://www.pcori.org/glossary
	Patient Network News	This bi-weekly newsletter provided by the Office of Health and Constituent Affairs is intended to inform you of current FDA-related information on medical product: *approvals *labeling changes *safety warnings *ways to participate on upcoming public meetings *ways to comment on proposed regulatory guidance *other information of interest to patients and patient advocates. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#P-1
	Patient Partners	Patients who are representative of the population of interest in a study, as well as their family members, caregivers, and the organizations that represent them. Patient partners are not to be confused with patient subjects; patient partners are members of the research team and involved in the planning, conduct, and dissemination of the research, whereas patient subjects are those individuals enrolled in the study as participants. https://www.pcori.org/glossary
	Patient Preferences	Preferences expressed by patients with regards to decisions concerning their health care. https://www.fda.gov/about-fda/cdrh-patient-science-and-engagement-program/list-patient-preference-sensitive-priority-areas

PPRNs	**Patient-Powered Research Networks**	PPRNs are operated and governed by patient groups and their partners and are focused on particular conditions or populations. https://www.pcori.org/glossary
	Patient Volunteer	A patient volunteer has a known health problem and participates in research to better understand, diagnose, treat, or cure that disease or condition. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
	Patients	Individuals who have or have had the condition under study; it may include patient surrogates or caregivers as well. It does not necessarily mean, but does not exclude, patient advocates or patient navigators. https://www.pcori.org/glossary
	Patients and Public Stakeholders	The patient and public stakeholders involved as the intended user of the tool and/or resource, as applicable. https://www.pcori.org/glossary
	Payers	Those who function as financial intermediaries in the health system, including private insurers and public insurers, and organizations representing insurers, such as America's Health Insurance Plans.https://www.pcori.org/glossary
PFA	**PCORI Funding Announcement**	PCORI grant funding announcements https://www.pcori.org/glossary
PCORnet	**Patient-Centered Outcomes Research Network**	A network of institutions with a goal of transforming data gathered from routine patient care across their participating health systems into a consistent format, the PCORnet Common Data Model, to enable rapid response to research-related questions. Patient partners participate in PCORnet governance as well as all phases of the research process. https://www.pcori.org/glossary
PECC	**PCORnet Engagement Coordinating Center**	*see PCORnet Engagement Core
PGx	**Pharmacogenetics/Pharmacogenomics**	Pharmacogenomics (sometimes called pharmacogenetics) is a field of research that studies how a person's genes affect how he or she responds to medications. Its long-term goal is to help doctors select the drugs and doses best suited for each person. It is part of the field of precision medicine, which aims to treat each patient individually.https://www.nigms.nih.gov.
PFT	**Pulmonary Function Test**	Lung function tests (also called pulmonary function tests) include a variety of tests that check how well the lungs work. The most basic test is spirometry. This test measures the amount of air the lungs can hold. The test also measures how forcefully one can empty air from the lungs.https://www.lung.org/lung-health-diseases/lung-procedures-and-tests/lung-function-tests
PII	**Personally Identifiable Information**	any data that could potentially identify a specific individual. Any information that can be used to distinguish one person from another and can be used to deanonymize previously anonymous data
	Phase I trials	An experimental drug or treatment in a small group of people (20–80) for the first time. The purpose is to evaluate its safety and identify side effects. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms

	Phase II trials	The experimental drug or treatment is administered to a larger group of people (100–300) to determine its effectiveness and to further evaluate its safety. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
	Phase III trials	The experimental drug or treatment is administered to large groups of people (1,000–3,000) to confirm its effectiveness, monitor side effects, compare it with standard or equivalent treatments. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
	Phase IV trials	After a drug is licensed and approved by the FDA researchers track its safety, seeking more information about its risks, benefits, and optimal use. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
PHI	**Personal Health Information**	The HIPAA Privacy Rule provides federal protections for personal health information held by covered entities and gives patients an array of rights with respect to that information. https://www.hhs.gov/answers/hipaa/what-is-phi/index.html
PLACER	**Phased Large Awards for Comparative Effectiveness Research**	PCORI grant focused on high-quality comparative clinical effectiveness research (CER) projects that will address critical decisions faced by patients, caregivers, clinicians, and stakeholders across the health and healthcare community and for which there is insufficient evidence. https://www.pcori.org/funding-opportunities/announcement/phased-large-awards-comparative-effectiveness-research-placer-cycle-3-2022
	Phases of Clinical Trials	Clinical trials are conducted in “phases.” The trials at each phase have a different purpose and help researchers answer different questions. https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics
	Placebo	An inactive pill or liquid that looks like the new treatment but does not have any treatment value from active ingredients. This is sometimes called a “sugar pill.” In some studies, participants may be assigned to take a placebo rather than the study medication. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
	Placebo effect	Sometimes people taking a study medication receive benefits that are not from the chemicals in the medicine. This is called a “placebo effect.” For example, if a participant feels hopeful about a treatment, he or she may be more likely to notice positive changes than negatives ones. A researcher’s hope may also sway a participant’s response. Double-blind research design helps minimize the placebo effect. https://www.nccih.nih.gov/health/placebo-effect
	Plausible Hypotheses	Likely alternative explanations or ways of accounting for program results, meaning those involving influences other than the program. https://cdc.gov/evaluation/guide/glossary/index.htm
POC	**Point of Care**	Testing and treating of patients at sites close to where they live. Rapid diagnostic tests are used to obtain immediate, on-site results. The success of the concept relies on portable, rapid diagnostic devices that provide results directly to the user, which allows health care workers in remote areas to test and treat patients at the time of the visit. https://www.nibib.nih.gov/science-education/glossary/p

	PopMedNet	A software application that provides users secure, customized, private protocols with file transfer capabilities. Users are able to query data held by partners in participating data networks or nodes via menu-driven analysis and distribution of complex analytics programs. https://www.popmednet.org/
	Population	The set of units to which the results of a survey apply. https://cdc.gov/evaluation/guide/glossary/index.htm
	Post-Market Surveillance	The process by which a drug's safety is monitored on an ongoing basis after a drug is approved by FDA. Post-market surveillance looks to identify problems that were not observed or recognized before approval and any problems that may arise because a drug may not be used as described in the drug labeling, or because a drug is being manufactured incorrectly. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#P-1
PBRN	**Practice Based Research Network**	groups of primary care clinicians and practices working together to answer community-based health care questions and translate research findings into practice. PBRNs engage clinicians in quality improvement activities and an evidence-based culture in primary care practice to improve healthcare https://www.ahrq.gov/research/findings/factsheets/primary/pbrn/index.html
	Pre-Clinical Data	Before a drug can be tested in people in the United States; sponsors (drug manufacturers, research institutions, and other organizations that develop drugs) must show FDA results of testing they have done in laboratory animals and what they propose to do for human testing. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#P-1
	Prediabetes	The amount of glucose, also called sugar, in your blood is higher than normal but not high enough to be called diabetes. Glucose is a form of sugar your body uses for energy. Too much glucose in your blood can damage your body over time. If you have prediabetes, also called impaired fasting glucose (IFG) or impaired glucose tolerance (IGT), you are more likely to develop type 2 diabetes, heart disease, and stroke. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#P-1
	Preference Sensitive Decisions	Decisions in which there are multiple diagnostic or treatment options, and the decision about which option to pursue depends upon the particular preferences of the decision maker. This concept has an important role in assessing when patient preferences information is of value. https://www.fda.gov/about-fda/cdrh-patient-science-and-engagement-program/list-patient-preference-sensitive-priority-areas
	Preferences	The concept of "preferences" may be defined differently by different stakeholders. The definition of preference may also differ depending on the method by which preferences are elicited. Preferences are defined as "qualitative or quantitative statements of the relative desirability or acceptability of attributes that differ among alternative health interventions", a definition consistent with the use of the term in patient preference literature. https://www.fda.gov/about-fda/cdrh-patient-science-and-engagement-program/list-patient-preference-sensitive-priority-areas

PI	**Principal Investigator**	The lead researcher and primary contact for the study. https://www.pcori.org/glossary
	Probability Sampling	The selection of units from a population based on the principle of randomization. Every unit of the population has a calculable (non-zero) probability of being selected. https://cdc.gov/evaluation/guide/glossary/index.htm
	Process Evaluation	The systematic collection of information to document and assess how a program was implemented and operates. https://cdc.gov/evaluation/guide/glossary/index.htm
	Program Evaluation	The systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development. https://cdc.gov/evaluation/guide/glossary/index.htm
	Program Goal	A statement of the overall mission or purpose(s) of the program. https://cdc.gov/evaluation/guide/glossary/index.htm
PMO	**Program Management Office**	The PMO coordinates all internal and external communication platforms and provides leadership and infrastructure support and coordination and is housed at DCRI within the CC. https://starcrn.org/frequently-asked-questions/
	Programmatic Review	A review of the scientific portion(s) of the application to ensure that it meets programmatic requirements. These may include but are not limited to: presence of a CER question; absence of a cost effectiveness question; and, when applicable, addressing the specific research question in a targeted funding announcement. https://www.pcori.org/funding-opportunities/what-you-need-know-apply/glossary
	Project Manager Meeting	A monthly meeting for STAR CRN Site Project Managers to discuss administrative and technical requirements and issues. https://starcrn.org/frequently-asked-questions/
	Project Type	Types of PCORI projects include: **Research projects** are designed for two purposes: to improve patient outcomes by comparing two or more care approaches and to enhance the methods and infrastructure needed to support such research. **Engagement in research projects** are designed to encourage better integration of patients and other stakeholders into the research process, and they are not research studies. **Research infrastructure projects** are designed to either (1) enhance and optimize network infrastructure and promote sustainability goals, or (2) develop the role of patient- or participant-driven organizations to advance health outcomes improvement and guide the clinical and care-delivery research enterprise. **Dissemination and implementation projects** either (1) support the uptake of findings from funded research in real-world practice to improve health care and health outcomes, or (2) promote the use of effective shared decision-making approaches in healthcare settings to help patients and their clinicians make choices that are best for them. Projects marked as **Other Evidence Products** fall within our broader research synthesis efforts, which take advantage of a wide variety of tools to pull together and analyze results for public use. https://www.pcori.org/glossary

	Propriety	The extent to which the evaluation has been conducted in a manner that evidences uncompromising adherence to the highest principles and ideals (including professional ethics, civil law, moral code, and contractual agreements). https://cdc.gov/evaluation/guide/glossary/index.htm
PHI	**Protected Health Information**	health data created, received, stored, or transmitted by HIPAA-covered entities and their business associates in relation to the provision of healthcare, healthcare operations and payment for healthcare services. https://www.hhs.gov/answers/hipaa/what-is-phi/index.htm
PHQ/ PHQ2	**Patient Health Questionnaire**	Tool that measures suicidality and other patient health concerns https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/patient-health
PRO	**Patient reported outcome**	A patient reported outcome (PRO) is any report that comes directly from a patient about how they function or feel in relation to a health condition. PROs are often used in clinical trials to evaluate the effectiveness of medical products (e.g., drugs, medical devices, biological products, etc.). This call will provide you with an introduction to PROs and PRO instrument development. Definition adopted from https://www.pcori.org/sites/default/files/UMD-NORD-Telecon-Two-Patient-Reported-Outcomes.pdf
PROMIS	**Patient-Reported Outcomes Measurement Information System**	The Common Fund's **Patient-Reported Outcomes Measurement Information System (PROMIS)** program created new paradigms for how clinical research information is collected, used, and reported. PROMIS addressed a need in the clinical research community for a rigorously tested patient reported outcome (PRO) measurement tool that uses recent advances in information technology, psychometrics, and qualitative, cognitive, and health survey research to measure PROs such as pain, fatigue, physical functioning, emotional distress, and social role participation that have a major impact on quality-of-life across a variety of chronic diseases. For current information about PROMIS, please visit the HealthMeasures https://commonfund.nih.gov/promis/index
	Protocol	A Protocol is a carefully designed plan to safeguard the participants' health and answer specific research questions .https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms
	Public Abstract	A summary of the research plan or research findings that is written for, and accessible to, a general lay audience. https://www.pcori.org/glossary
	Purchasers	Those who purchase health benefits for employees and their dependents, including individual businesses as well as local, state, regional, and national business groups, coalitions that represent businesses, and health coalitions. https://www.pcori.org/about-us/our-programs/engagement/public-and-patient-engagement/pcoris-stakeholders
QI	**Quality Improvement**	Quality improvement is the framework used to systematically improve care. Quality improvement seeks to standardize processes and structure to reduce variation, achieve predictable results, and improve outcomes for patients, healthcare systems, and organizations. Structure includes things like technology, culture, leadership, and physical capital; process includes knowledge capital (e.g., standard operating procedures) or human capital (e.g., education and training).

		https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Quality-Measure-and-Quality-Improvement-
	Qualitative Data	Data representing information and concepts that are not represented by numbers. They are often gathered from interviews and focus groups, personal diaries and lab notebooks, maps, photographs, and other printed materials or observations. https://www.nnlm.gov/guides/data-glossary/qualitative-data
	Quantitative Data	Observations that are numerical. https://cdc.gov/evaluation/guide/glossary/index.htm
	Quarantine	To separate and restrict the movement of people who were exposed to a contagious disease to see if they become sick. This helps protect the public by preventing exposure to people who have or may have a contagious disease. https://www.cdc.gov/quarantine/quarantineisolation.html
	Quasi-Experimental Design	Study structures that use comparison groups to draw causal inferences but do not use randomization to create the treatment and control groups. The treatment group is usually given. The control group is selected to match the treatment group as closely as possible so that inferences on the incremental impacts of the program can be made. https://cdc.gov/evaluation/guide/glossary/index.htm
QPM	**Query Pricing Model**	PCORnet Coordinating Center model to collect data on query prices across sites, with the ultimate goal of establishing a common pricing model to promote research efficiency across the Network. https://pcornet.org/data/
	Random Digit Dialing	In telephone interviewing, a technique used to select a sample. A computer, using a probability-based dialing system, selects and dials a number for the interviewer. https://cdc.gov/evaluation/guide/glossary/index.htm
	Randomization	A process in which researchers evenly assign study participants into a group receiving the experimental treatment being studied, and others into a group receiving standard or no treatment. Participants are assigned to a group based on chance, not choice. https://cdc.gov/evaluation/guide/glossary/index.htm
RCT	**Randomized Controlled Trial**	An experiment in which participants are randomly allocated to receive one of two (or more) diagnostic, preventive, therapeutic, or palliative interventions and are then followed to determine the effects of the intervention. https://www.pcori.org/glossary
	Reasonable Costs	A cost may be considered reasonable if the nature of the goods or services acquired or applied is appropriate and justifiable. The amount involved reflects the action that a prudent person would have taken under the circumstances prevailing at the time the decision to incur the cost was made. https://www.pcori.org/glossary
RIC	**Recruitment Innovation Center**	NCATS-funded center in recruitment and retention strategies to improve both the quality of future clinical trials and to raise awareness of the value of research thereby increasing trial enrollment and health outcomes across America. https://trialinnovationnetwork.org/recruitment-innovation-center/

	Regression Artifacts	Pseudo-changes in program results occurring when persons or treatment units have been selected for the program on the basis of their extreme scores. Regression artifacts are a threat to internal validity. https://cdc.gov/evaluation/guide/glossary/index.htm
	Regulatory Agency	A public authority or government agency responsible for exercising autonomous authority over some area of human activity in a regulatory or supervisory capacity. An independent regulatory agency is a regulatory agency that is independent from other branches or arms of the government. Regulatory agencies deal in the area of administrative law—regulation or rulemaking (codifying and enforcing rules and regulations and imposing supervision or oversight for the benefit of the public at large). https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#R-1
	Reliability	The extent to which a measurement, when repeatedly applied to a given situation consistently produces the same results if the situation does not change between the applications. Reliability can refer to the stability of the measurement over time or to the consistency of the measurement from place to place.https://cdc.gov/evaluation/guide/glossary/index.htm
	Renewed Support	Approval of an additional funding period for the same project within the approved project period. The original agreement will remain in place and additional funds obligated near the end of each funding period. Any funds remaining on the contract prior to the new obligation will remain available for the recipient's use. https://www.pcori.org/glossary
	Replicate Sampling	A probability sampling technique that involves the selection of a number of independent samples from a population rather than one single sample. Each of the smaller samples is termed a replicate and is independently selected on the basis of the same sample design. https://cdc.gov/evaluation/guide/glossary/index.htm
	Research	A study done to answer a question. Scientists do research when they're not sure what will work best to help people with an illness. Other words to describe clinical research are "clinical trial," "protocol," "study," and "experiment." https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#R-1
RD	**Research Derivative Database**	A database of clinical and related data derived from the Vanderbilt University Medical Center's (VUMC) clinical systems and restructured for research. Data is repurposed from VUMC's enterprise data warehouse, which includes data from StarPanel, VPIMS, and ORMIS (Operating Room Management Information System), EPIC, Medipac, and HEO among others. The medical record number and other person identifiers are preserved within the database. Data types include reimbursement codes, clinical notes and documentation, nursing records, medication data, laboratory data, encounter and visit data, among others. Output may include structured data points, such as ICD codes and encounter dates, semi-structured data such as laboratory tests and results, or unstructured data such as physician progress reports. VUMC HRPP: Research Derivative

RFA	**Request for Applications**	a formal statement that invites applications in a defined area to accomplish specific program objectives and outlines the amount of funds set aside for competition, the estimated number of awards to be made, and the deadline for submitting an application.NIH Grant Policy Statement.
ROCKET	**Research Organization Collaboration & Knowledge Exchange Toolkit (VUMC)**	Discontinued Vanderbilt University Medical Center cloud content management platform for Vanderbilt faculty, staff, students, trainees & affiliates.
	Research Team	A group of people organized to function cooperatively to design and conduct research. https://www.pcori.org/glossary
	Resource Focus	These help to identify how the tool or resource can be used to support engagement efforts in patient-centered outcomes research. https://www.pcori.org/glossary
	Resources	Assets available and anticipated for operations. They include people, equipment, facilities, and other things used to plan, implement, and evaluate programs. https://www.cdc.gov/evaluation/guide/glossary/index.htm
	Resubmission	An application that was submitted and received a summary statement but was not funded and is being resubmitted to the same funding agency for new consideration. https://www.pcori.org/glossary
	Risk Tolerance	The impact of uncertainty on decisions and applies to both benefits and harms. A notion reflecting the degree to which a patient would accept greater probability or severity of a harm in exchange for a given benefit, while maximum acceptable risk and minimum required benefit are quantitative measures of this notion. https://doi.org/10.1007/s40271-016-0210-z
RTI	**Research Triangle Institute**	RTI International is an independent, nonprofit research institute dedicated to improving the human condition. Our vision is to address the world's most critical problems with science-based solutions in pursuit of a better future. Clients rely on us to answer questions that demand an objective and multidisciplinary approach—one that integrates expertise across the social and laboratory sciences, engineering, and international development https://www.rti.org/about-us
RXNorm		common language for clinical drugs and links its names to many of the drug vocabularies commonly used in pharmacy management and drug interaction software. https://www.nlm.nih.gov/research/umls/rxnorm/index.html
	Sample Size	The number of units to be sampled. https://cdc.gov/evaluation/guide/glossary/index.htm
	Sample Size Formula	An equation that varies with the type of estimate to be made, the desired precision of the sample and the sampling method, and which is used to determine the required minimum sample size. https://cdc.gov/evaluation/guide/glossary/index.htm
	Sampling Error	The error attributed to sampling and measuring a portion of the population rather than carrying out a census under the same general conditions. https://cdc.gov/evaluation/guide/glossary/index.htm

	Sampling Frame	Complete list of all people or households in the target population. https://cdc.gov/evaluation/guide/glossary/index.htm
	Sampling Method	The method by which the sampling units are selected (such as systematic or stratified sampling). https://cdc.gov/evaluation/guide/glossary/index.htmhttps://cdc.gov/evaluation/guide/glossary/index.htm
	Sampling Unit	The unit used for sampling. The population should be divisible into a finite number of distinct, non-overlapping units, so that each member of the population belongs to only one sampling unit. https://cdc.gov/evaluation/guide/glossary/index.htm
SARS-Co V-2	**Severe Acute Respiratory Syndrome Coronavirus 2**	a virus that causes respiratory illness in humans; can cause the disease COVID-19 https://www.cdc.gov/sars/index.html
SDoH	**Social Determinants of Health**	conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. https://www.ama-assn.org/system/files/ama-assn-equity-guide.pdf
	Secondary Data	Data collected and recorded by another (usually earlier) person or organization, usually for different purposes than the current evaluation. https://cdc.gov/evaluation/guide/glossary/index.htm
	Selection and Program Interaction	The uncharacteristic responsiveness of program participants because they are aware of being in the program or being part of a survey. This interaction is a threat to internal and external validity. https://cdc.gov/evaluation/guide/glossary/index.htm
	Selection Bias	When the treatment and control groups involved in the program are initially statistically unequal in terms of one or more of the factors of interest. This is a threat to internal validity. https://cdc.gov/evaluation/guide/glossary/index.htm
	Setting and Program Interaction	When the setting of the experimental or pilot project is not typical of the setting envisioned for the full-scale program. This interaction is a threat to external validity. https://cdc.gov/evaluation/guide/glossary/index.htm
	Shared Decision Making	An intervention or approach that draws on and presents available evidence to inform patients of available treatment options and their risks and benefits, and either engages patients in a decision-making process with their clinician or promotes their ability to engage in such a process. https://www.pcori.org/glossary
	Single- or Double-Blind Studies	Single- or double-blind studies (also called single- or double-masked studies) are studies in which the participants do not know which medicine is being used, so they can describe what happens without bias. https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms

	Single-Blind Research Design	A study in which one party, either the investigator or participant, is unaware of what medication or intervention the participant is taking; also called single-masked study. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#S-1
SNOMED CT	**Systematized Nomenclature of Medicine Clinical Terms**	SNOMED CT contains more than 357,000 health care concepts with unique meanings and formal logic-based definitions organized into hierarchies. A unique semantic type, included in parentheses, identifies each hierarchy in the fully specified name of every concept in the hierarchy. The fully populated code system list with unique descriptions for each concept contains more than 957,000 descriptions. Approximately 1.37 million semantic relationships exist to improve the reliability and consistency of data retrieval. https://mmshub.cms.gov/measure-lifecycle/measure-specification/specify-code/SNOMED-CT
	Sponsors	Clinical trials are sponsored or funded by various organizations or individuals, including physicians, foundations, medical institutions, voluntary groups, and pharmaceutical companies, as well as Federal agencies such as NIH, FDA, the Department of Defense, and the Department of Veterans Affairs. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#S-1
SRTR	**The Scientific Registry of Transplants Recipients**	SRTR supports the ongoing evaluation of solid organ transplantation in the United States. SRTR designs and carries out data analyses and maintains two websites for the public to disseminate organ transplant information. https://srtr.transplant.hrsa.gov/
SAC	**Stakeholder Advisory Council**	The SAC provides input to CRN Leadership and investigators to help generate research questions, review research proposals, assist in the conduct of research, monitor progress and help disseminate information. The primary purpose of the AV is to provide meaningful input from the patient and clinician stakeholder viewpoint to assure that the CRN's activities are patient-centered and informed by practicing clinicians. https://starcrn.org/frequently-asked-questions/
SET	**Stakeholder Engagement Team**	Faculty and staff managing stakeholder engagement at CRN-level, site stakeholder engagement reps (i.e., staff or faculty), designated patient representatives who lead implementation of person-centered engagement plan; identify and engage a variety of stakeholders (patients, caregivers, clinicians, etc.), collaborate with SAC, facilitate implementation of stakeholder engagement https://starcrn.org/frequently-asked-questions/
SFA	**Stress First Aid**	a framework to improve recovery from stress reactions, both in oneself and in coworkers. https://www.ptsd.va.gov/professional/treat/type/stress_first_aid.asp
	Stakeholders	People or organizations that are invested in the program or that are interested in the results of the evaluation or what will be done with results of the evaluation. https://cdc.gov/evaluation/guide/glossary/index.htm
SGLT2i	**Sodium-glucose cotransporter-2 inhibitor**	SGLT2i stands for sodium-glucose cotransporter-2 inhibitors. They are a type of prescription medication used to treat type 2 diabetes in adults. SGLT2i are also called gliflozins.
STAR CRN	**Stakeholders, Technology, and Research Clinical Research Network**	The CRN centered at Vanderbilt University Medical Center (VUMC) and comprised of VUMC, Vanderbilt Healthcare Affiliated Network (VHAN), Meharry Medical Center, Duke university, the

		University of North Carolina at Chapel Hill, Health Sciences South Carolina, Wake Forest, and the Mayo Clinic. https://starcrn.org/frequently-asked-questions/
	Standard	A principle commonly agreed to by experts in the conduct and use of an evaluation for the measure of the value or quality of an evaluation (e.g., accuracy, feasibility, propriety, utility). https://cdc.gov/evaluation/guide/glossary/index.htm
	Standard Deviation	The standard deviation of a set of numerical measurements (on an "interval scale"). It indicates how closely individual measurements cluster around the mean. https://cdc.gov/evaluation/guide/glossary/index.htm
	Standard Treatment	The treatment that medical professionals consider at the time of the study to be the most prevalent and best available treatment. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#S-1
	Standardized Format Interview	An interviewing technique that uses open-ended and closed-ended interview questions written out before the interview in exactly the way they are asked later. https://cdc.gov/evaluation/guide/glossary/index.htm
	Standardized Procedures	These are study rules that researchers must follow exactly for every participant, regardless of what each participant is used to. For example, if you normally take a medicine by injection but the experiment is testing the same medicine in pill form, the researcher must prescribe pills to you. The researcher cannot use a different method for you. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#S-1
	Statistical Analysis	The manipulation of numerical or categorical data to predict phenomena, to draw conclusions about relationships among variables or to generalize results https://cdc.gov/evaluation/guide/glossary/index.htm
	Statistical Model	A model that is normally based on previous research and permits transformation of a specific impact measure into another specific impact measure, one specific impact measure into a range of other impact measures, or a range of impact measures into a range of other impact measures. https://cdc.gov/evaluation/guide/glossary/index.htm
	Statistically Significant Effects	Effects that are observed and are unlikely to result solely from chance variation. These can be assessed through the use of statistical tests. https://www.simplypsychology.org/p-value.html
	Stratified Sampling	A probability sampling technique that divides a population into relatively homogeneous layers called strata and selects appropriate samples independently in each of those layers. https://cdc.gov/evaluation/guide/glossary/index.htm
	Study	Conducted by a principal investigator who is often a doctor. Members of the research team regularly monitor the participant's health to determine the study's safety and effectiveness. Other words to describe a study are "clinical trial," "protocol," "experiment," and "research." https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#S-1

	Study Registration	PCORI-funded studies are required to register in ClinicalTrials.gov (NCT) or the National Library of Medicine's Health Services Research Projects in Progress (HSRP) database. Study registration information includes study aims, patient population eligibility, interventions and comparators, outcomes measures, and, as required, participant recruitment status. https://www.pcori.org/glossary
	Subcontractor	An individual or group who takes a portion of a contract from the prime contractor (awardee) or from another subcontractor. https://www.pcori.org/glossary
	Subjective Data	Observations that involve personal feelings, attitudes, and perceptions. Subjective data can be measured quantitatively or qualitatively. https://cdc.gov/evaluation/guide/glossary/index.htm
	Surveys	A data collection method that involves a planned effort to collect needed data from a sample (or a complete census) of the relevant population. The relevant population consists of people or entities affected by the program (or of similar people or entities). https://cdc.gov/evaluation/guide/glossary/index.htm
SD	**Synthetic Derivative**	The Synthetic Derivative (SD) is Vanderbilt's fully de-identified repository of clinical data. It is a rich, multi-source database integrating data from across the enterprise. The database contains approximately 2.5 million electronic medical records. The SD also contains integrated genetic data made available through BioVU. https://www.vumc.org/dbmi/synthetic-derivative
	Systematic Review	A synthesis and critique of existing literature, which can identify evidence gaps and inform decisions regarding how to address these gaps. https://www.ncbi.nlm.nih.gov/books/NBK481583/
	Technical Abstract	A summary of the research plan that is written for scientists and researchers. https://writing.wisc.edu/handbook/assignments/writing-an-abstract-for-your-research-paper/
	Testing Bias	Changes observed in a quasi-experiment that may be the result of excessive familiarity with the measuring instrument. This is a potential threat to internal validity. https://cdc.gov/evaluation/guide/glossary/index.htm
	Transitional Care	A range of services designed to ensure continuity and promote safe and coordinated transitions between settings and clinicians. https://www.pcori.org/glossary
	Treatment Group	In research design, the group of subjects that receives the program. Also referred to as the experimental or program group. https://cdc.gov/evaluation/guide/glossary/index.htm
TIC	**Trial Innovation Center**	Provides consultation and research solutions to investigators who are collaborating with the Trial Innovation Network on multicenter clinical trials and studies. https://dcri.org/trial-innovation-center/
TIN	**Trial Innovation Network**	Innovation Centers focused on addressing roadblocks in clinical trials and accelerating the translation of novel interventions into life-saving therapies https://trialinnovationnetwork.org/

T1DM	**Type 1 Diabetes**	Diabetes mellitus type 1 (also known as type 1 diabetes, or T1DM; formerly insulin dependent diabetes or juvenile diabetes) is a form of diabetes mellitus that results from the autoimmune destruction of the insulin-producing beta cells in the pancreas. The subsequent lack of insulin leads to increased blood and urine glucose. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#T-1
TriNETX		TriNetX, LLC ("TriNetX") was founded on the idea that incorporating real-world data results in order to better trial design, improves the site selection and patient recruitment process and generates real-world evidence (RWE) to reduce the burden of disease around the world. Since TriNetX's inception in 2013, TriNetX supported life science companies and healthcare systems around the world, empowering researchers to find answers to their clinical questions and drive scientific discovery to improve patient lives.https://trinetx.com/
T2DM	**Type 2 Diabetes**	Type 2 diabetes, once called non-insulin-dependent diabetes, is the most common form of diabetes, affecting 90% to 95% of the 26 million Americans with diabetes. Unlike people with type 1 diabetes, the bodies of people with type 2 diabetes make insulin. But either their pancreas does not make enough insulin, or the body cannot use the insulin well enough. This is called insulin resistance. When there isn't enough insulin or the insulin is not used as it should be, glucose (sugar) can't get into the body's cells. When glucose builds up in the blood instead of going into cells, the body's cells are not able to function properly. https://www.fda.gov/patients/clinical-trials-what-patients-need-know/glossary-terms#T-1
	Uncertainty Attitude	A reflection of the degree to which uncertainty in the attributes of a treatment alters one's decisions about use of the treatment. Highly relevant to medical decision-making. https://doi.org/10.1177/0269216316647610
	Uncertainty Averse	Patients who are uncertainty averse react to uncertainty by decreasing their maximum acceptable risk for a given benefit, or by increasing their minimum required benefit for a given risk. https://doi.org/10.1177/0269216316647610
	Uncertainty Neutral	Patients whose maximum acceptable risk is not impacted by uncertainty are referred to as uncertainty neutral. https://doi.org/10.1177/0269216316647610
	Uncertainty Tolerant	Patients who are uncertainty tolerant react to uncertainty by increasing their maximum acceptable risk for a given benefit, or by decreasing their minimum required benefit for a given risk. https://doi.org/10.1177/0269216316647610
	Utility	The extent to which an evaluation produces and disseminates reports that inform relevant audiences and have a beneficial impact on their work. https://cdc.gov/evaluation/guide/glossary/index.htm
VICTR	**Vanderbilt Institute for Clinical and Translational Research**	Vanderbilt's virtual home for clinical and translational research. Supported by the Vanderbilt University Medical Center's Office of Research and the NIH sponsored Clinical and Translational Science Award (CTSA), the mission of the institute is to transform the way ideas and research discoveries make their way from origin to patient care. VICTR functions to help researchers and

		clinicians do their jobs better by providing tools and support to improve the quality of research, publications, grant writing, and training for future doctors and researchers.https://victr.vumc.org/
IMPH	**Vanderbilt Institute for Medicine and Public Health**	Connects research and teaching with policy and practical solutions by re-imagining and amplifying collaborations among more than 50 departments, 292 faculty, 208 staff, 110 graduate students, more than 21 centers, and all ten schools. The Institute reaches across the state, nation, and the global community to translate knowledge into better health. https://www.vumc.org/medicine-public-health/home

Additional Resources	
American Descendants of Slavery Advocacy Foundation	**American Descendants of Slavery Advocacy Foundation. (2022). Retrieved from** https://www.adosfoundation.org/
Asian Pacific Institute on Gender-Based Violence	**Asian Pacific Institute on Gender-Based Violence. (2022). *Census Data & Api Identities.* Retrieved from** https://www.api-gbv.org/resources/census-data-api-identities/.
California State University San Marcos	**California State University San Marcos. *Who is APIDA?* Retrieved from** https://www.csusm.edu/apidafsa/who_is_apida/index.html#:~:text=We%20use%20the%20term%20APIDA.as%20part%20of%20the%20community.
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