# RARE DISEASES CLINICAL RESEARCH NETWORK (RDCRN) POLICIES

Version: January 20, 2026

RARE DISEASES
CLINICAL RESEARCH NETWORK

# TABLE OF CONTENTS

RARE DISEASES
CLINICAL RESEARCH NETWORK

# NETWORK OVERVIEW

The Rare Diseases Clinical Research Network (RDCRN) consists of Rare Diseases Clinical Research Consortia (RDCRCs), a Data Management and Coordinating Center (DMCC), a Coalition of Patient Advocacy Groups (CPAG), other patient advocacy group (PAG) partners, and cooperative partners from the National Institutes of Health (NIH).

The RDCRCs, the DMCC, and their contact Principal Investigators (PIs) for the current funding cycle starting in 2025 are located at the following institutions:

| Abbreviation | Consortium | Name |
|---|---|---|
| ACT | Advancing Craniosynostosis Treatment Rare Diseases Consortium | Eric Chien-Wei Liao, MD, PhD<br>*Children's Hospital of Philadelphia, Philadelphia, PA* |
| ARDVARC | Advancing Rare Disorders: Vascular mAlformation Research Network with CaNVAS | Denise Adams, MD<br>*Children's Hospital of Philadelphia, Philadelphia, PA* |
| ARISEN | Autoimmunity, Rasmussen's, Inflammation & Status Epilepticus research Network | Grace Yoonheekim Gombolay, MD<br>*Emory University, Atlanta, GA* |
| BBDC | Brittle Bone Disorders Consortium | Brendan Lee, MD, PhD<br>*Baylor College of Medicine, Houston, TX* |
| BDCRC | Batten Disease Clinical Research Consortium | Erika Augustine, MD<br>*Kennedy Krieger Institute, Baltimore, MD* |
| CReATe | Clinical Research in ALS and Related Disorders for Therapeutic Development | Michael Benatar, MD, PhD<br>*University of Miami, Miami, FL* |
| DSC | Developmental Synaptopathies Consortium | Mustafa Sahin, MD, PhD<br>*Boston Children's Hospital, Boston, MA* |
| GLIA-CTN | The Global Leukodystrophy Initiative Clinical Trials Network | Adeline Vanderver, MD<br>*Children's Hospital of Philadelphia, Philadelphia, PA* |
| IMPACT | Initiation of a cohort to define pathogenic Mechanisms, Precision diagnosis And Complications of Thrombotic Microangiopathies: The IMPACT Study | Robert A. Brodsky, MD<br>*Johns Hopkins Medicine, Baltimore, MD* |
| MGNet | Rare Disease Network for Myasthenia Gravis | Henry Kaminski, MD<br>*George Washington University, Washington DC* |
| NASCARR | Network for Advancing Sex Chromosome Aneuploidy Research Readiness | Nicole Tartaglia, MD<br>*University of Colorado Denver* |
| PFN-STRIDE | Pediatric Fungal Network STudy of Rare Invasive fungal DisEases in | Brian Fisher, DO<br>*Children's Hospital of Philadelphia, Philadelphia, PA* |

| | | |
|---|---|---|
| | Immunocompromised Pediatric Patients | |
| RBDC | Rare Bronchiectatic Diseases Consortium | Kenneth Olivier, MD<br>*University of North Carolina at Chapel Hill, Chapel Hill, NC* |
| ROAR | Rare Organic Acidemias Research | V. Reid Sutton, MD<br>*Baylor College of Medicine, Houston, TX* |
| SP-CERN | Spastic Paraplegia Centers of Excellence Research Network | Darius Ebrahimi-Fakhari, MD, PhD<br>*Boston Children's Hospital, Boston, MA* |
| DMCC | The Data Management and Coordinating Center | Maurizio Macaluso, MD, DrPH<br>*Cincinnati Children's Hospital Medical Center, Cincinnati, OH* |
| BVMC* | Brain Vascular Malformation Consortium | Helen Kim, PhD<br>*University of California San Francisco, San Franscisco, CA* |
| CPIC* | Congenital and Perinatal Infections Consortium | David Kimberlin, MD<br>*University of Alabama at Birmingham, Birmingham, AL* |
| CEGIR* | Consortium of Eosinophilic Gastrointestinal Disease Researchers | Marc Rothenberg, MD, PhD<br>*Cincinnati Children's Hospital Medical Center, Cincinnati, OH* |
| NAMDC* | North American Mitochondrial Disease Consortium | Michio Hirano, MD<br>*Columbia University, New York, NY* |
| PHEFREE* | Phenylalanine Families and Researchers Exploring Evidence | Cary Harding, MD<br>*Oregon Health & Science University, Portland, OR* |
| UCDC* | Urea Cycles Disorders Consortium | Andrea Gropman, MD<br>*St. Jude Children's Research Hospital, Memphis, TN* |

*Consortium is currently in a no cost extension.

Much of the below information is taken directly from the RFA (RFA-TR-24-021) and NOFO (PAR-24-206) of the DMCC and RDCRCs, respectively.

The RDCRCs intend to advance the diagnosis, management, and treatment of rare diseases with a focus on clinical trial readiness and early and timely diagnosis. Each RDCRC promotes highly collaborative, multi-site, patient-centric, translational and clinical research. Each RDCRC must conduct a natural history study and have a minimum of two but no more than four multi-site clinical research projects. Additionally, each RDCRC study should move the field closer to the design and/or implementation of pivotal clinical trials or earlier diagnosis. Each RDCRC targets at least three rare diseases, disorders, syndromes, or conditions (referred to in this document as rare diseases).

RDCRCs may address clinical trial readiness by supporting studies that validate clinical research tools such as biomarkers or clinical outcome assessment measures that are fit-for-purpose within a defined context of use relevant to the clinical trials. Clinical trial readiness studies may also propose to expand the knowledge of disease natural history necessary for clinical trial design and can include characteristics for stratification or determining inclusion and exclusion criteria; the stage of disease progression that may be responsive to treatment; and data needed for determining sample size through power calculations. The use of animal models and basic science studies are out of scope. The use of in vitro models must be relevant to clinical endpoints. Any clinical trial proposed as part of a RDCRC must meet ICO-specific rules for clinical trials.

The RDCRCs are expected to play a leadership role in career enhancement; attract new researchers for the rare diseases field and contribute to the development of future research leaders. In addition, patient and stakeholder (parent, caregiver, support, and advocacy group) experiences, perspectives, needs and priorities must be meaningfully incorporated into decisions and activities of the RDCRC. To facilitate this, each RDCRC must form partnerships with patient advocacy groups. Patient advocacy group partners specific to the RDCRC participate in individual RDCRC activities and participate in Coalition of Patient Advocacy Group (CPAG) activities.

Overall, the DMCC's role within the RDCRN is to facilitate and support the activities of each individual RDCRC along with trans-network activities that broadly facilitate the advancement of rare disease research via four avenues: administrative support, data management support, clinical research support and patient engagement, and broad dissemination of information.

The DMCC manages the RDCRN operational environment for RDCRCs to conduct their work. RDCRCs must not replicate services provided by the DMCC.

## NIH Partners

The Rare Diseases Clinical Research Network is funded by the Division of Rare Diseases Research Innovation (DRDRI) in the National Center for Translational Sciences (NCATS), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Heart, Lung and Blood Institute (NHLBI), the National Institute of Dental and Craniofacial Research (NIDCR), the National Human Genome Research Institute (NHGRI), the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), the Office of Research on Women's Health (ORWH), and the NIH Office of the Director (OD).

## NETWORK GOVERNANCE

The RDCRN **Governing Committees** responsible for the strategic leadership, policy direction, and oversight of the network include the **Joint Leadership Team (JLT)**, the network **Steering Committee (SC)**, and the **Coalition of Patient**

**Advocacy Groups (CPAG) Steering Committee**. Each body plays a distinct yet interdependent role in advancing the network's goals by integrating perspectives from investigators, patient advocacy representatives, the Data Management and Coordinating Center (DMCC), and NIH leadership.

These governing committees establish the policies, priorities, and collaborative expectations that guide the RDCRN. They also provide a formal mechanism for coordination across consortia, ensuring that network-wide activities remain aligned with NIH directives and the broader rare disease research ecosystem.

### Joint Leadership Team (JLT)

The Joint Leadership Team (JLT) consists of:

- Steering Committee Chairs and Co-Chairs
- CPAG Chairs
- DMCC Principal Investigators
- NCATS RDCRN Program Officer

The JLT will:

- Review proposals for new or revised network policies.
- Screen potential cross-network research projects and recommend them to the Steering Committee for consideration.
- Review and approve proposals to use the RDCRN Contact Registry for recruitment or communication purposes.
- Review and approve proposals for new Standing Committees, Work Groups, and Special Interest Groups (SIGs)
- Exercise delegated authority from the Steering Committee to create and dissolve Standing Committees, Work Groups, and SIGs as needed to advance network priorities.
- Discuss issues escalated from across the network and identify potential solutions to be discussed with the Steering Committee and/or CPAG Steering Committee.

Operations of the JLT:

- Serves as the Executive Committee of the RDCRN.
- Meets monthly to discuss strategic issues and make executive decisions guiding the network's operations.

### Steering Committee

The Network Steering Committee (SC) consists of:

- RDCRC Principal Investigator(s) (PI)
- Chair(s) of the Coalition of Patient Advocacy Groups (CPAG)
- The PI(s) of the DMCC
- NIH Program Director(s)/Scientist(s) from participating institutes

The Network SC will:

- Identify scientific and policy issues that need to be addressed at the Network level
- Identify broad issues in the field of rare diseases research that can be addressed by the Network
- Review and approve all RDCRN-wide policies

Operations of the RDCRN SC:

- The SC will have monthly web conferencing calls.
- The SC will have semiannual meetings, one in person and one virtually
- The minutes for all SC discussions will be documented and posted in Box.
- The voting members of the RDCRN include the PI(s) of each RDCRC (each RDCRC has one collective vote), the PI(s) of the DMCC (the DMCC has one collective vote), the Chair(s) of the CPAG SC (one collective vote), the RDCRN NIH Program Director, the NIH Institute or Center (IC) Program Officials and Project Scientists (collectively this group has one vote).
- A quorum of the RDCRN SC comprises 75% of the voting members.
- Procedures for the election of the SC chairs can be found in the section: Election of RDCRN Steering Committee Chairperson.

*Election of RDCRN Steering Committee Chairperson*

The position of Co-Chair of the Steering Committee of the Rare Diseases Clinical Research Network (RDCRN) will be selected by the membership of the Steering Committee as one of the responsibilities set forth in PAR-24-206. The Steering Committee will have three (3) Co-Chairs. One Co-Chair position will rotate off annually, and a new Co-Chair will be elected each year to maintain continuity in leadership.

Principles:

1. The term for a Co-Chair will be Jan 1 – Dec 31. When an individual is selected for Co-Chair, he/she is committing to a three-year total commitment.

2. The term of the position of Co-Chair will be 3 years in duration. The newly elected Co-Chair will work collaboratively with the other Co-Chairs during the next year serving as co-leaders of the SC.

3. The individuals holding the positions of Co-Chair must be current members of the RDCRN Steering Committee.

4. Co-Chairs must be a Principal Investigator of one of the RDCRN Consortia.

5. The elections require a vote by the Steering Committee.

6. A quorum of the voting members of the RDCRN Steering Committee must vote in each election if a new Co-Chair is to be selected. Results from elections involving less than a quorum will be disregarded and cannot be used to elect a new Co-Chair.

Process:

1. Names of individuals proposed to serve as second Co-Chair of the RDCRN Steering Committee (hereafter "Nominees") will be solicited from the Steering Committee Members prior to the conclusion of the term of office of the current Chair, or if a Chair or Co-Chair vacancy arises for any reason. The names of Nominees will be submitted in writing or by electronic mail directed to the DMCC. If a new Chair or first Co-Chair is to be selected because either existing role is unable to fill his/her responsibilities, the same process below will be followed to identify nominees.

2. The DMCC will confirm the nominations with the Nominee to ensure their acceptance. All eligible Nominees will be offered an opportunity to confirm or decline.

3. An electronic ballot will be prepared by the DMCC and will include the names of all eligible Nominees who confirmed their acceptance.

4. The electronic ballot will be sent to all voting RDCRN Steering Committee Members by e-mail. The DMCC will re-contact and, if necessary, use an alternative method to contact any Member that fails to respond.

5. The DMCC will tally the votes and will inform the RDCRN NCATS Program Officer regarding the results. The nominees with the most votes will be selected as the new co-chair.

6. In the event of a tie, the names of the Nominees who equally received the most votes will be placed on a second ballot.

7. The secondary ballot will be sent by e-mail to all voting RDCRN Steering Committee Members as described in Step 3 (above).

8. All Members will cast their vote using the secondary ballot as described in Step 4 (above).

9. Votes will be tallied as described in Step 5 (above). If not, the results of the election process will be discussed at the next monthly RDCRN Steering Committee meeting and further steps will be considered.

10. The NIH NCATS Program Officer and DMCC will announce the elected second Co-Chair to the members of Steering Committee.

11. The newly elected Nominee will take over as second Co-Chair at the Steering Committee meeting in January following the election.

For elections occurring at the end of the funding cycle, where the grant year ends in the middle of the calendar year, the elected co-chairs will remain for the duration of the calendar year as long as their consortium is actively funded. If any co-chair's consortium's funding lapses, the SC may operate with two co-chairs until the next calendar year, or an ad hoc election could take place at the discretion of the Joint Leadership Team.

### Coalition of Patient Advocacy Groups (CPAG) Steering Committee

The CPAG SC consists of:

- One PAG representative from each RDCRC
- Two PI representatives
- DMCC PDs/PIs
- NCATS RDCRN Program Director
- NIH Program Officials / Project Scientists

The CPAG SC will:

- Identify scientific and policy issues relevant to patient advocacy.
- Ensure the patient and family voice is represented in decision-making.
- Facilitate the development of activities that will benefit the entire CPAG membership.

Operations of the CPAG SC:

- The committee will have monthly web conferencing calls.
- The notes for committee meetings will be documented, sent to full CPAG membership via the CPAG Chat and posted in the CPAG Hub.
- The voting members of the committee include the PAG representative(s) of each active RDCRC (each RDCRC has one collective vote).
- A quorum of the CPAG SC comprises 75% of the voting PAG members.
- PAG representatives on the committee are selected by the respective RDCRC PI(s).
- The two PI representatives are nominated and voted on by the PAG members of the committee.

## NETWORK POLICIES

Requests can be made to propose a new policy or change an existing policy at any time, but a written recommendation will need submitted and approved prior to implementation.

Procedures:

- To propose a new policy or change an existing policy, a written recommendation should be sent to the JLT.

- The JLT will review and discuss the proposal.
- If the JLT supports the proposal, it will submit it to the network Steering Committee (SC) for approval.
    - If the JLT does not support the proposal, requestor will be informed that the proposal has been rejected.

## Key Information

All RDCRCs are required to share key information with the DMCC and keep the information up to date on a regular basis or whenever changes are made. Specific key information needed is listed in the Network Operations Manual saved here.

## Network Collaborative Infrastructure

The **Collaborative Infrastructure** of the RDCRN supports the practical implementation of the network's scientific and operational goals. It provides the structure through which members collaborate, share expertise, and deliver on cross-consortia priorities identified by the governing committees.

This infrastructure consists of **Standing Committees**, **Work Groups**, and **Special Interest Groups (SIGs)**, each serving a distinct role in facilitating collaboration

### Committees

**Standing Committees** are expected to operate throughout the five-year funding period and focus on sustained, network-wide functions. Standing Committees in cycle 5 include the **Early Career Education Collaborative (ECEC).** RDCRCs are expected to designate representatives to the network's Standing Committees . The establishment of additional Standing Committees will be proposed to the JLT in writing using the Work Group/ Standing Committee Proposal Template. Once reviewed by the JLT, proposed committees are voted on by the SC.

Each Committee must maintain a charter based on the RDCRN Charter Template, that will be reviewed and approved by the JLT. Committees are encouraged to provide relevant updates or ask for feedback on activities/ deliverables from the Network SC and CPAG SC.

### Work Groups

**Work Groups** are time-limited, deliverable-focused groups that address discretionary cross-consortia priorities and network business. Their objectives must contribute directly to achieving the research mission of the RDCRN to advance the diagnosis, management, and treatment of rare diseases with a focus on clinical trial readiness and early and timely diagnosis. Work groups can include representatives from DMCC, consortia, NIH, and patient advocacy groups (PAGs).

New Work Groups may be proposed by any RDCRN member using the Work Group/ Standing Committee Proposal Template. Work Group proposals require the identification of one or more leads and sponsorship from DMCC leadership. Proposals are reviewed by the JLT, and only those that align with network priorities and available resources are approved. Once approved, a DMCC Project Manager is assigned to support the Work Group and together with the lead(s) develop a charter, based on the RDCRN Charter Template, that will be reviewed and approved by the JLT.

Each Work Group must designate at least one lead. Work Groups may appoint co-leads to share responsibilities, provided that roles are clearly defined in the charter. When co-leads are identified, one must be designated as the primary point of contact for communication and accountability.

Work Groups operate according to their charters and are monitored by the JLT. Each Work Group is expected to provide progress updates to the JLT on a quarterly basis, including a final progress report, using the JLT Progress Report template. During these reviews, the JLT will assess whether the group is making sufficient progress toward its objectives. If a Work Group is not on track, the JLT may recommend corrective actions, up to and including adjustments to leadership or early closure of the group. In addition, Work Groups are encouraged to provide relevant updates or ask for feedback on deliverables from the Network SC and CPAG SC. Work Groups close once their deliverables are complete.

Administrative support for RDCRN Work Groups will be provided by the DMCC Project Management team. For a detailed breakdown of responsibilities, reference the NOM.

For a current list of Work Groups, meeting times, minutes, and resources, credentialed users can visit the RDCRN Committees page on the Members Landing Page .

## Special Interest Groups

**Special Interest Groups (SIGs)** are voluntary, discussion-based forums that allow members of the RDCRN to connect around shared areas of interest. Unlike Committees and Work Groups, SIGs are not required to have charters or produce deliverables; their primary purpose is to facilitate knowledge sharing, networking, and exploration of emerging topics that may inform future collaborative activities.

To initiate a SIG, at least one lead must be identified, and a brief purpose statement should be shared with the JLT. The JLT will review the statement to ensure that the proposed SIG does not duplicate the scope of existing groups and that there is sufficient network-wide interest. If the JLT supports the formation of the SIG, the group will be registered by the DMCC and included in network communications so members may participate.

SIGs may include representatives from DMCC, consortia, NIH, and patient advocacy groups (PAGs). When co-leads are identified, one must be designated as the primary point of contact for communication and accountability.

The DMCC may provide light-touch administrative support, such as meeting logistics, as resources allow. A SIG may be dissolved if interest is no longer evident, or if recommended by the JLT to avoid duplication of effort.

## Network-wide surveys/workshops/events initiated by Committees, Work Groups or SIGs

If any Committees, Work Group or SIG wants to initiate a network-wide activity such as a survey, a virtual workshop/event, or other activity open to the network as a whole, the chair(s) will send a proposal to the JLT specifying the purpose/objectives of the survey and a draft of the survey questions for their review and approval prior to sending the survey.

## Meeting Code of Conduct

The RDCRN is dedicated to maintaining an inclusive, safe, and respectful environment for everyone attending or participating in events such as annual meetings, webinars, and other events. We do not tolerate harassment of people in any form, and we empower all participants in our community to actively engage in creating a friendly and safe environment for all.

As an attendee, presenter, researcher, sponsor, or guest at RDCRN events or programs organized by RDCRN, we expect everyone will:

- Recognize that the RDCRN consists of a community of professionals with different disciplines and career paths
- Exercise consideration and respect toward all persons in their speech and actions
- Encourage and contribute to productive scientific discourse. Refrain from demeaning, discriminatory, or harassing behavior, speech, and imagery
- Seek advice from NIH staff if you have questions

## Data Sharing

Advancing rare disease research by freely sharing high-value data is a critical goal of the RDCRN program. Deidentified data collected within this network will become a resource for the greater rare disease research community and will be made available through a federal data repository to the scientific community, stakeholders and other relevant partners in a manner that meets all NIH human subject's protection, data safety and data sharing requirements in accordance with the Final NIH Policy for Data Management and Sharing (NOT-OD-21-013).

The RDCRN has developed guidance and resources on data sharing best practices for the network. A document entitled “RDCRN Suggestions for Establishing Data Sharing and Data Management Guidance for Individual

Consortia", outlines key factors for consortia to consider when establishing internal data sharing plans. Another resource, "Principles of Data Sharing Checklist", lists elements that need to be incorporated into informed consent language, in agreements between the administrative core and its sites, and in consortium policies that govern data sharing, use, and publication to facilitate future data sharing and use. An overview of these resources can be found on the RDCRN website.

Many NIH Institutes and Centers (ICs) have specific data sharing policies. A table listing NIH data sharing policies in effect can found here; it includes policies at the NIH, IC, division, and program levels that apply to broad sets of investigators and data.

Two other data sharing policies relevant to the RDCRN are highlighted below.

The Genomic Data Sharing Policy expects that large-scale genomic research data from NIH-funded studies involving human specimens, as well as non-human and model organisms, will be shared through a publicly available data repository. All studies with human genomic data should be registered in dbGaP, and the data should be submitted to an NIH-designated data repository. Non-human data may be submitted to any widely used data repository.

The NDAR Grantees Data Sharing Policy states that all data resulting from autism-related NIH-funded research involving human subjects are expected to be submitted to the National Institute of Mental Health Data Archive (NDA), along with appropriate supporting documentation to enable efficient use of the data.

Additional information on data sharing expectations and best practices can be found in the RDCRN Network Operations Manual (NOM) saved here.

## Protocol Numbering and Reviews

Because of the number and variety of research protocols in the RDCRN, the management of protocols by DMCC and NIH requires file versioning and protocol numbering standards. The DMCC will assign each protocol a unique number at the time of initial receipt. Additionally, each consortium is expected to have their protocols reviewed and approved by the DMCC and NIH. More information on protocol numbering and protocol reviews can be found in the NOM.

## Database Access

Study personnel, regardless of role, must view the database training conducted by the DMCC and complete the attestation prior to database access being granted. Training is available on the Members Landing Page.

### Read/Write Access across Multiple Sites

Study personnel who have write/edit access for site-level data for all sites participating in a study must have the written authorization from the protocol PIs at each site to have write/edit access to their site-level data. To ensure that this written authorization is in place, the protocol must include a statement defining the level of access for specific role(s). The named individual(s) fulfilling that role must be included on the Delegation of Authority log at the site where the individual(s) requiring write/edit access are based, but are not expected to be named in the protocol.

## Licensing for Data Collection Instruments

All databases will be created using the RDCRN template REDCap database to ensure alignment with RDCRN data standards. The DMCC will build data collection instruments into REDCap databases as provided by the consortia, though modifications may be necessary to meet data standard requirements. The DMCC will not alter any data collection instruments that are licensed or trademarked; these will be implemented exactly as provided by the consortia. If any measures require additional licensing, the consortium is responsible for covering associated costs and ensuring compliance with all licensing agreements. Some instruments may be available through the publicly accessible REDCap Shared Library, which the DMCC may use for database import. However, it remains the consortium's responsibility to verify that appropriate permissions and licenses are in place for use of any instrument.

## Branding Guidelines

RDCRN Brand Guidelines have been developed to provide guidance on how and when to use the RDCRN and consortium logos. Guidelines, logos, and templates can be found in the Brand Central folder on Box.

## RDCRN Websites

The DMCC will provide resources to each consortium to create and maintain a consortium-specific public website. The consortium will be responsible for providing the necessary information for the website to be created. The necessary information needed to create the website is outlined in the Network Operations Manual saved here.

Any publications listed on the Consortium RDCRN website must reflect the current NIH Grants Policy Statement. More specific information about necessary acknowledgements can be found in the Publications section of this document.

The DMCC team will work with consortia teams to select photos for use on RDCRN-hosted websites. Consortia teams may collaborate with PAGs to provide patient/family photos for use. Please reach out to Dakota.Campbell@cchmc.org to discuss this process.

Consortia are asked to adhere to the following photo policies:

1. Patient photos
   - Authentic patient photos are preferred on the RDCRN websites. Please note that any photos in which patients are identifiable are considered to contain protected health information (PHI). The consortium's administrative coordinating center (admin core) must obtain a signed photo release from those identifiable in a photo before an image may be used on an RDCRN website. Please use the photo release form provided by the DMCC.

2. Professional headshots
   - The admin core can request and provide professional headshots from individuals as desired for "Meet the Team" or other static web pages. The admin core should:
     - Collect photos from individuals and provide them to the DMCC team.
     - Ask individuals providing photos to check with their institution's media office and confirm that they have permission to provide the photo for use on the consortium's website.

3. Group photos
   - Posed group photos featuring 5 or more people do not require individually signed photo releases. Notice/knowledge regarding how the photo(s) may be used is recommended when photos are taken.

## Publications

The RDCRN Publication Policy stipulates that a RDCRC has the following responsibilities:

1. Each RDCRC will address definitions and policies for authorship within their consortium. Definitions should include specific publication types, and definition of authorship types and roles. Polices will address author responsibilities and procedures for timely consortium review for quality assurance.

2. Each RDCRC is responsible to ensure that the manuscript content and format meets accepted scientific standards, and that appropriate NIH regulations are followed. Adherence to NIH Public Access Policy requires scientists to submit final peer-reviewed journal manuscripts that arise from NIH funds to the digital archive PubMed Central upon acceptance for publication. The NIH Public Access Policy applies to any manuscript that:
   - Is peer-reviewed;
   - And, is accepted for publication in a journal on or after April 7, 2008;
   - And, arises from:
     - Any direct funding[1] from an NIH grant or cooperative agreement active in Fiscal Year 2008 or beyond, or;
     - Any direct funding from an NIH contract signed on or after April 7, 2008, or;

- Any direct funding from the NIH Intramural Program, or;
- An NIH employee.

[1] "Direct" funding means costs that can be identified specifically with a particular sponsored project, or that can be directly assigned to such activities relatively easily with a high degree of accuracy.

When awardees list a publication in the progress report publication list of an RPPR or a renewal application, they are claiming that the publication directly arises from that award and the awardee is responsible for the public access compliance of the listed publications.

See NIH Public Access Policy details at https://publicaccess.nih.gov/policy.htm

It is the responsibility of the author to ensure that the publication is submitted to PubMed Central. Instructions related to the submission process can be found at http://publicaccess.nih.gov/

3. Each RDCRC will ensure that sponsors and RDCRN (including the DMCC) are appropriately acknowledged.

   All materials (promotional materials, publications and internet sites) related to the RDCRN program must include a statement acknowledging that the consortium is part of RDCRN and an acknowledgement of NIH Cooperative Agreement Award (or grant) support. The language should also acknowledge the DMCC in supporting the research activities of the RDCRN.

   The following language is recommended to be included in manuscripts for acknowledging the DMCC support for RDCRN related research projects:

   Research reported in this [publication, release] was supported by [name of the Institute, Center, or other funding component] of the National Institutes of Health under grant number [specific NIH grant number in this format: R01GM012345].

   Each consortium should work with their funding Institute for the specific text that is required in acknowledging the funding of their consortium. The DMCC has provided examples for each consortium saved in Box. Required text is indicated in the consortium's notice of award.

4. Each RDCRC will notify the NIH Project Scientists from their funding institutes, the DMCC, and the NCATS Program Officer when a manuscript has been accepted for publication.

5. Publications that describe the RDCRN and its functions, objectives and outcomes (that are not focused on a specific protocol or Consortium), require approval of the RDCRN Steering Committee.

These policies are equally applicable to press releases.

## RDCRN Alumni

At the conclusion of RDCRN.4 (summer 2025), investigator teams affiliated with consortia whose performance period was ending had the opportunity to apply for an RDCRN Alumni status. Alumni teams received five years of access to the RDCRN cloud environment. Alumni teams are responsible for managing their members' use of the tools to operate independently in the RDCRN operational environment. Alumni are required to meet semiannually with the DMCC to maintain transparency of their activities in the RDCRN operational environment.

The DMCC is responsible for account management, security management, and data storage. The DMCC is also available for troubleshooting technical challenges beyond the expertise of an Alumni team.

Alumni groups are not permitted to vote on network matters but are permitted to attend committee meetings, including the in-person semi-annual meetings at their own expense.