CARRA
2023-2025 Research Agenda

The 2023-2025 CARRA Strategic Plan outlines the establishment and maintenance of a scientific agenda that guides CARRA's work. Following this recommendation, the Executive Committee formed a Research Agenda Task Force to identify unmet needs and knowledge gaps that should be prioritized through CARRA's research endeavors. Through a process that included significant participation from members, external partners, and other key stakeholders, the Research Agenda Task Force generated a broad scientific agenda independent of specific disease entities that would address critical unmet research needs, support current and future research and partnership opportunities, and enable prioritization of resource utilization and future growth. Four categories emerged and are detailed below.

CARRA RESEARCH AGENDA PRIORITIES:

Methodologies and Approaches

- Team/collaborative science
- Basic/translational research
- Rare disease focus
- Health services and education research
- Innovative methods
- Implementation science

Public Health and Systemic Biases

- Epidemiology
- Explicit and implicit bias
- Racism
- Social determinants of health
- Diversity/inclusion within CARRA research

Therapeutics

- Interventional trials
- Clinical decision-making support
- Treatment adherence

Understanding Disease

- Prevention of rheumatologic disease
- Fundamental mechanisms of disease
- Comorbidities and complications
- Long-term outcomes

As the Research Agenda neared completion, CARRA worked with the Arthritis Foundation (AF), and assembled a second group of key opinion leaders tasked with developing a targeted research agenda focused solely on inflammatory arthritis that aligned with the overall plan. The resulting documents, in conjunction with CARRA's strategic plan, will guide the organization's internal research decisions, external research collaborations, and funding initiatives to address unmet needs.

Research priorities in the Inflammatory Arthritis Research Agenda:

Precision Medicine

- Biomarker identification; diagnostic and prognostic
- Starting/stopping medication
- Safety and the impact of use of specific medications (e.g., TNF-I in non-systemic JIA)

Patient Outcomes and Outcome Measures

- Long-term outcomes; impact on childbearing, occupation, college, marriage, delays vs. peers, growth, and reproductive health
- Transition
- Health-related quality of life (HRQOL)
- Environmental factors
- Patient-reported outcomes (PROs)
- Tools/outcome measure development, implementation, and ongoing validation

Epidemiology

- Use of the Registry (artificial intelligence and data science)

Representativeness

- Social determinants of health
- Equitable participant representation in the Registry

Treatment Development

- Working with the Food and Drug Administration (FDA) on acceptable trial designs in pediatric patients
- Evidence development (use of Registry and community data)

Comparative Effectiveness Research

- Consensus Treatment Plan (CTP) Program (development, revision, and implementation)

APPROACH

Task forces conducted focus groups comprising key stakeholders to facilitate meaningful discussions in line with CARRA's mission, vision, and values. Participants represented subject matter experts, researchers (including early career investigators), current and past CARRA leaders and board members, committee leaders, registry leadership, patient advocacy groups, and patients and caregivers. The Inflammatory Arthritis Research Agenda (IARA Task Force) also included individuals with specific expertise in juvenile arthritis and co-morbidities, biomarkers, precision medicine, epidemiology, comparative effectiveness research, mental health, health disparities, and health care delivery.

CARRA and the Arthritis Foundation further prioritized the arthritis research agenda using a questionnaire that mapped research categories and knowledge gaps to the patient journey. Through this effort, IARA Task Force identified knowledge gaps and priorities that were then organized into categories detailed above.

The IARA has been mapped to the overall Research Agenda to highlight areas of significant overlap, particularly around methodological approaches. Those areas of intersection are depicted in the summary table shown below:

	Will my child get a rheumatic disease? AND what can I do to prevent it?	I was just diagnosed, what is my best treatment option?	I have lived with this disease for a while, now what?	I have so much to think about!	What about my long-term health?
CARRA Research Agenda	Epidemiology Prevention Fundamental mechanisms of disease Social determinants of health Basic/translational	Team and collaborative science Interventional trials Innovative methods Implementation science clinical-decision making Explicit and implicit bias Rare disease focus	Clinical decision making Treatment adhere adherence Comorbidities and complications Social determinants of health Long-term outcomes	Health services and education research Long-term outcomes Racism Diversity and inclusion within CARRA research	Long-term outcomes Comorbidities and complications Health services and education research
CARRA-AF Inflammatory Arthritis Research Agenda	Epidemiology Precision medicine Representation Patient outcomes and outcome measures	Treatment development Comparative effectiveness research Representation Epidemiology Precision medicine	Comparative Effectiveness Research (CER) Patient outcomes and outcome measures Treatment development Precision medicine	Patient outcomes and outcome measures Comparative Effectiveness Research (CER)	Treatment development Representativeness Patient outcomes and outcome measures