### Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG)

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<th>Arthritis Patient Partnership with Comparative Effectiveness Researchers</th>
<th>CCFA Partners Patient Powered Research Network</th>
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<td>Greater Plains Collaborative</td>
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Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG)

Description
The Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG) brings together patients, clinicians, investigators, and other stakeholders within PCORnet to focus on research areas with crosscutting relevance. The ASIS CRG is organized by Research Interest Groups (RIGs) with an initial focus on three areas: 1) pathway to diagnosis; 2) comparative effectiveness of biologic (immunosuppressive) agents; and 3) reproductive concerns. ASIS CRG aims are as follows:

- Advance PCOR, CER and pragmatic research in ASIS using PCORnet assets (common data model, distributed research network, scientific expertise, coordinating center)
- Develop functioning teams to develop PCORnet research studies around priority areas
- Other aims include developing common data elements relevant to ASIS conditions for inclusion in the PCORnet common data model (CDM), engaging stakeholders, and assisting with queries to the PCORnet Front Door

RIG 1—Pathway to Diagnosis (Predictive analytics for establishing diagnoses of autoimmune/systemic inflammatory diseases)
Lead: Antoine G. Sreih, MD

For patients with autoimmune and systemic inflammatory diseases substantial delays in diagnoses are extremely common and often result in poor clinical outcomes. This RIG aims to understand patients’ pathways to diagnosis and develop algorithms to identify patients at risk of developing a specific autoimmune/inflammatory disease using predictive analytics and machine learning capabilities. This RIG seeks to identify predictive patterns of structured data in large databases to assist clinical decision making. The ultimate goal of this RIG/project is to prevent or minimize delays in diagnosis and improve clinical outcomes for patients with autoimmune and systemic inflammatory diseases.

The Pathway to Diagnosis RIG is led by Antoine G. Sreih, MD, a rheumatologist at the University of Pennsylvania and an expert in computable phenotypes. The RIG is developing a protocol that works across several diagnoses, utilizes the power and data within PCORnet, and leads to grant submissions and funding. We plan to pilot this project in vasculitis (preliminary data and feasibility) and then quickly scale the project up to include other autoimmune and inflammatory conditions using CDRNs and elements from within the PCORnet Common Data Model.

RIG 2—Comparative Effectiveness of Biologic (Immunosuppressive) Agents
Lead: Jeffrey R. Curtis, MD, MS, MPH

Safety concerns and uncertainty about clinical effectiveness for biologics, biosimilars and other immunosuppressive therapies are dominant factors for both patients and clinicians to effectively make informed treatment decisions. Moreover, patients often value treatment outcomes and prioritize decision-making related to domains (e.g., fatigue) that do not always align with physicians’ decision-making processes and assessments of treatment response (e.g., swollen joints by rheumatologists,
autoimmune and systemic inflammatory syndromes collaborative research group (asis crg)

colonoscopy results by gastroenterologists). There is little clinical and comparative effectiveness/safety
data to guide clinician and patient decision making. In general, treatment guidelines for biologic use in
arthritis, inflammatory bowel disease (ibd), and vasculitis emphasize general management principles or
make “grouped” medication class recommendations for all biologics, ignoring potentially important
differences in their mechanisms of action and associated implications for safety and effectiveness.
Guidelines also often fail to provide evidence-based recommendations for specific therapies or patient
types. This lack of consensus about the best treatment strategy is confusing and frustrating for clinicians
and patients alike, resulting in widespread variation in care. Recommendations made by the institute of
medicine (iom), the american gastroenterological association (aga), the american college of
rheumatology (acr) and the agency for healthcare research and quality (ahrq) have prioritized
studies of pharmacological management of asis conditions with biologics and biologic-like agents as a
top priority for cer.

this rig is led by dr. jeff curtis and includes the pcornet demonstration project “harnessing
pcornet to study comparative effectiveness and safety of biologic therapies” (pi: jeff curtis, uab),
nicknamed the choice study: comparative health outcomes in immune-mediated diseases
collaborative. this rig will build on the work of the choice study to include other networks and
conditions, such as multiple sclerosis.

rig 3—reproductive concerns
lead: megan e. b. clowse, md, mph

the concerns, attitudes, preferences, and treatment adherence of patients of childbearing age
affected by asis conditions is largely unknown. in addition, there remain large questions about how
best to treat asis conditions during pregnancy, and the impact of these illnesses on pregnancy
outcomes. this rif is examining this important area that has significant interest from patients, clinicians,
and drug manufacturers alike and will build on work currently in process by megan clowse (mid-south
cdrn at duke) with vasculitis (v-preg registry) and arthritispower™ ar-power prpn (survey of
patients of childbearing age with inflammatory arthritis). megan clowse is leading the reproductive
concerns rig to apply for nibh and other funding to scale and include other conditions in such studies.

asis crg co-leads:
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