

Challenges to performing pragmatic community-based autism research: A pragmatic explanatory continuum indicator summary evaluation of the NIMH ASD PEDS network

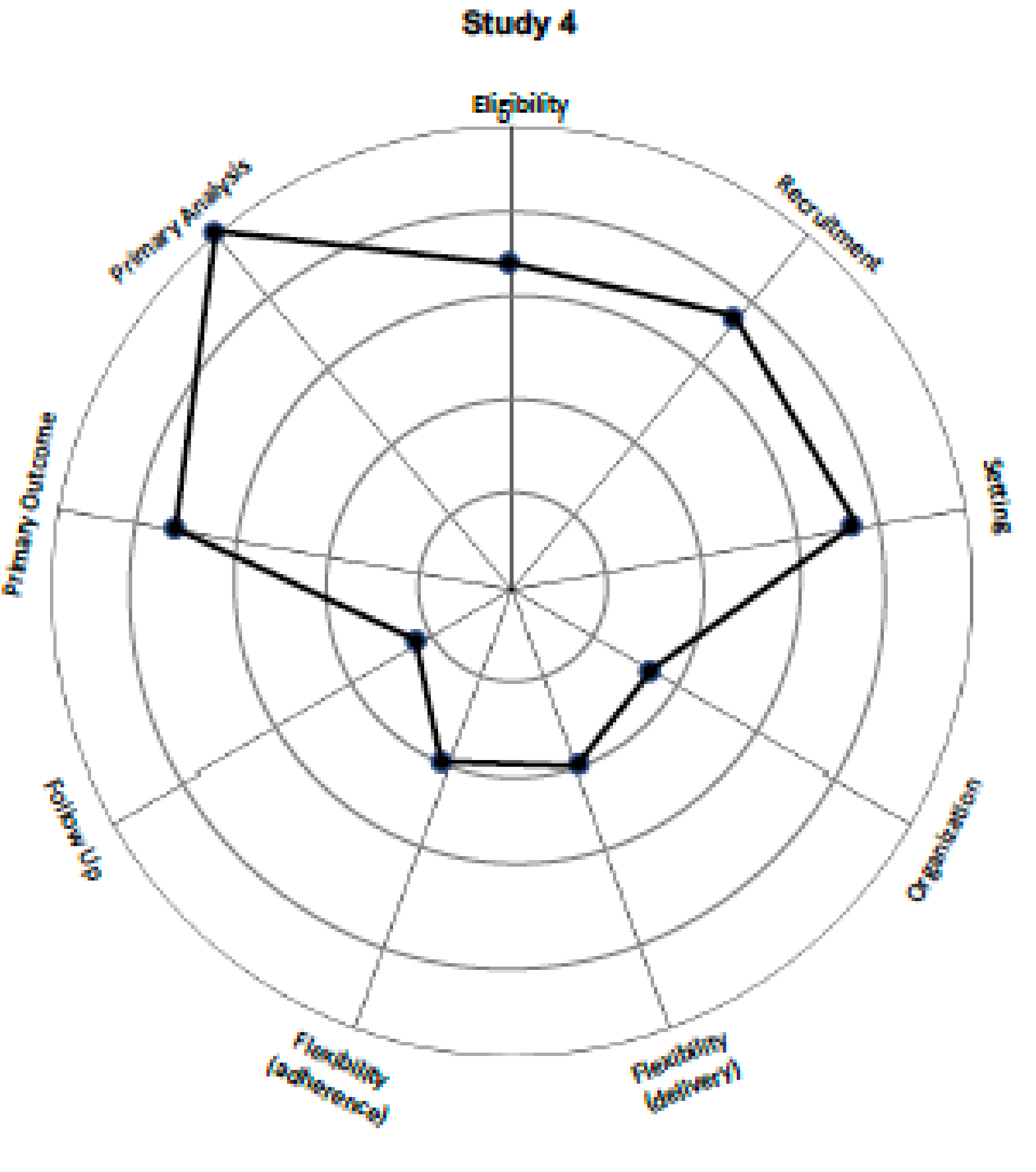
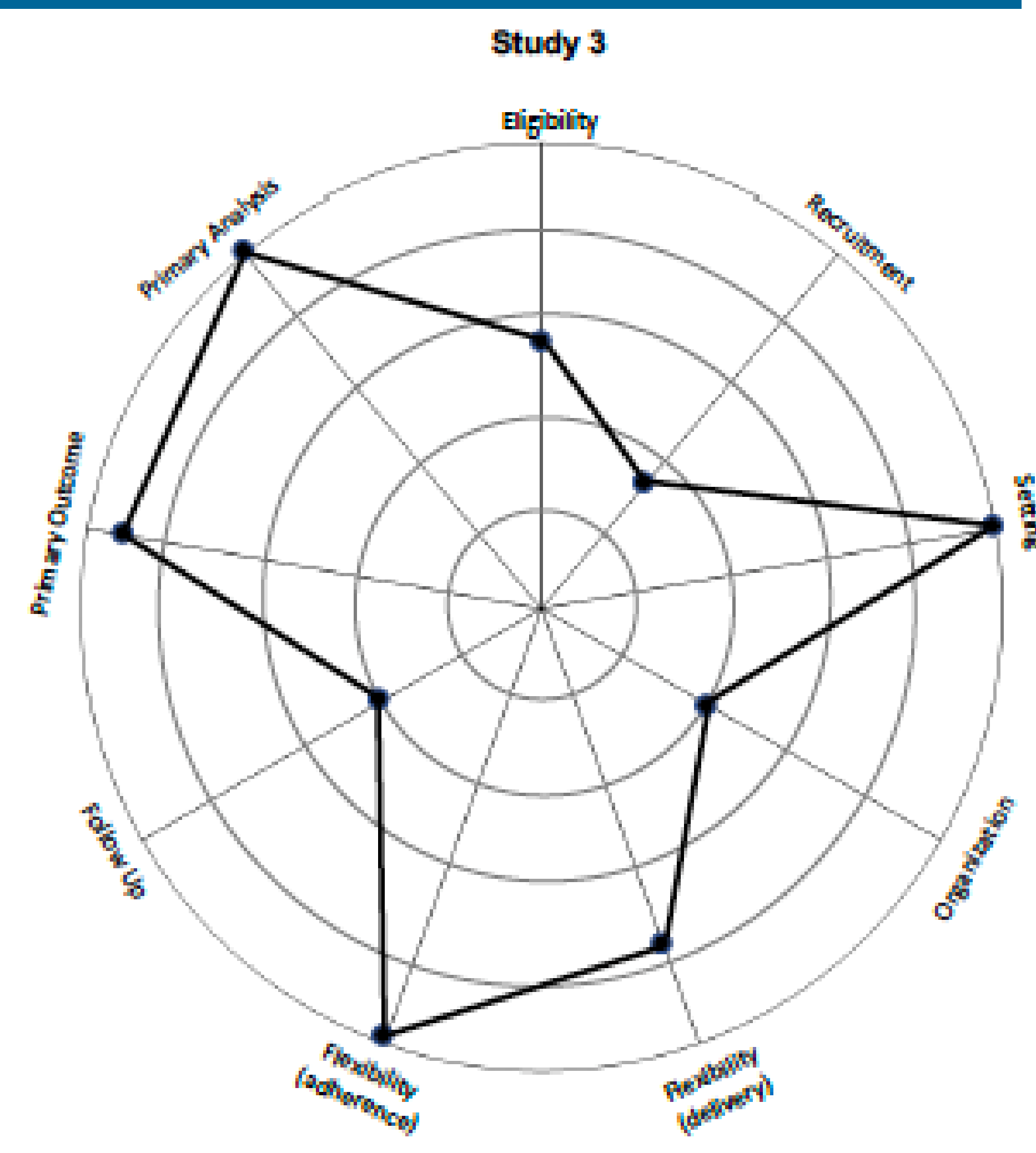
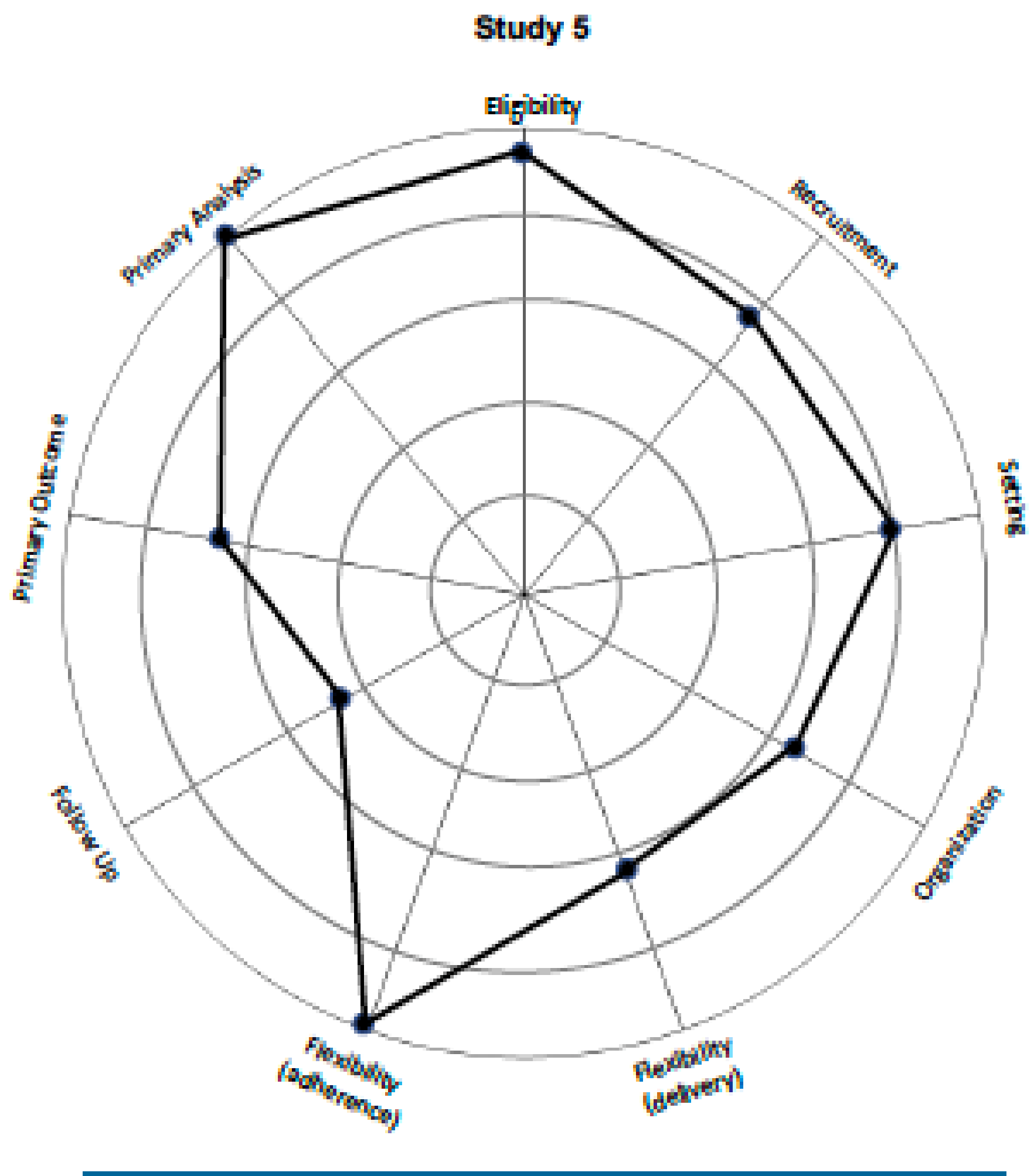
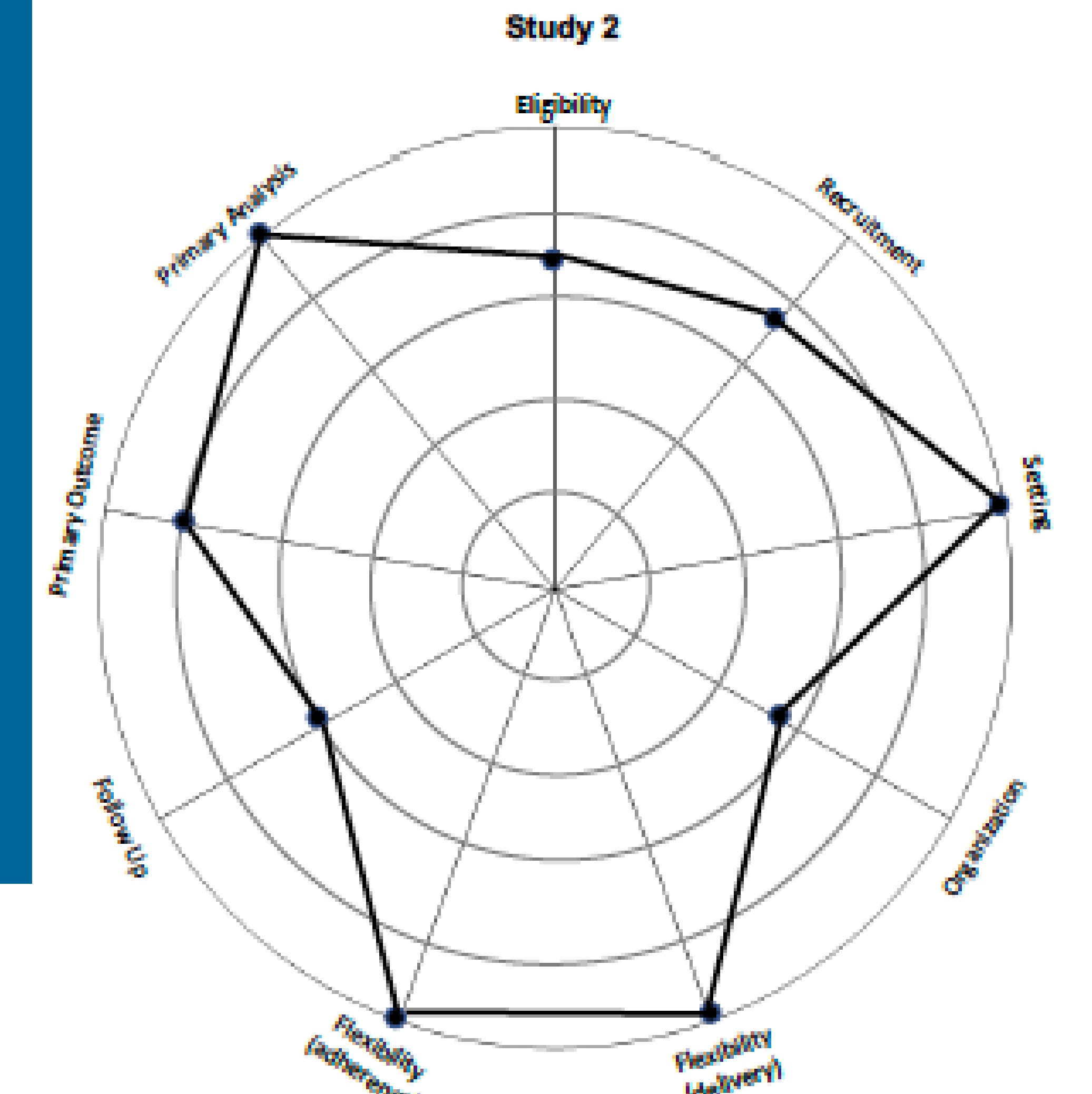
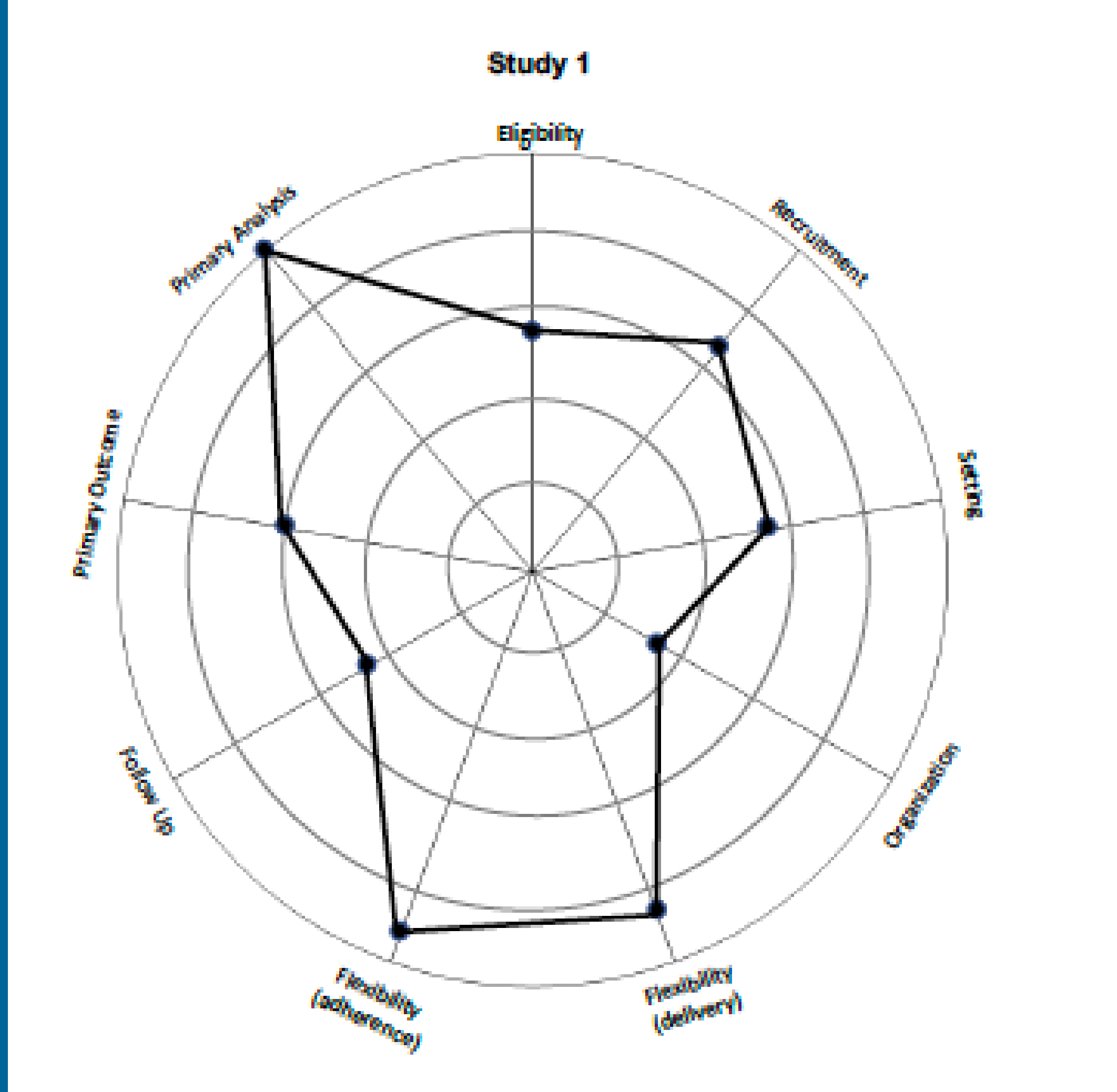
Background
 In 2014, the NIMH's Autism Spectrum Disorder Pediatric, Early Detection, Engagement and Services (ASD PEDS) Network was formed to develop and test systems innovations that rapidly engage young children with ASD in diagnostic and treatment services. Five studies across nine states were funded - each testing a different model of service engagement (e.g., online screening, navigation, enhanced identification) that holds promise for transforming ASD detection and service delivery systems. In addition to measuring the impact of interventions, an in-depth understanding of study design – specifically how closely each study reflects “real-world” practice - is critical for future dissemination and implementation efforts. This study represents one of several efforts to enhance interpretation of network findings. Specifically, we evaluate where each study falls on the pragmatic (i.e. “real-world”) to explanatory (i.e. least pragmatic, or “ideal condition”) continuum to inform future implementation efforts and identify research priorities for ASD services.

Methods
 We used the Pragmatic Explanatory Continuum Indicator Summary – 2 (PRECIS-2) to assess four ASD PEDS Network studies. First, investigator teams completed the Template for Intervention Description and Replication (TIDieR) checklist for their specific study. Second, a group of independent reviewers with expertise in community ASD services and trial design (n=4) reviewed checklists and rated each study on the nine PRECIS constructs (e.g., recruitment, setting, resources needed for delivery), from 1 (most “pragmatic”) to 5 (most “explanatory”). Third, a modified Delphi was used to reach agreement on each study in each domain.

Results
 There was considerable variation across sites across PRECIS domains. The average PRECIS score was 3.5 (range 2.9 – 4.1). Domains rated most pragmatic (i.e. most reflecting usual care) were “inclusiveness of analysis” (M= 5.0, SD= 0.1) and “adherence to the intervention” (M=4.2, SD=1.3). Domains rated most explanatory (i.e. different from usual care) were “resources needed for delivery” (M=2.1, SD=0.7) and “follow-up measurements” (M=2.2, SD=0.7).

Discussion
 Overall, the ASD PEDS Network studies were slightly more explanatory than pragmatic. Results suggest that the explanatory domains of “organization” (i.e. setting) and “follow-up” (i.e. outcomes) may pose particular challenges for conducting pragmatic trials focused on early detection and service access for ASD. If the goal is to increase pragmatic research trials and “real-world” applicability, then future research might benefit from using PRECIS-2 during trial design, developing more pragmatic outcome

The PRECIS-2 domains of study setting and outcomes may pose particular challenges for conducting pragmatic trials focused on autism detection and access to services.



Most Pragmatic Domains:

- Inclusiveness of analysis
- The majority of studies employed an intention-to-treat analysis
- Adherence to the intervention
- Majority of studies allowed practitioners to implement the intervention with strict adherence protocols

Most Explanatory Domains:

- Resources needed for delivery
- Studies provided significant material and personnel support to sites, which were far outside usual care
- Follow-up measurements
- Many measures were collected that are not part of usual care

Domains with Greatest Variability:

- Flexibility of adherence
- Delivery of the intervention

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 Drs. Broder-Fingert, Barnett, Stadnick and Locke are fellows with the Implementation Research Institute (IRI), at the George Warren Brown School of Social Work, Washington University in St. Louis; through an award from the National Institute of Mental Health (R25 MH080916-08).