



**Report of Breakout Sessions and  
Discussion:**

**Recruitment and Retention**

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# Key Survey Themes Discussed

- ▶ Importance of careful upfront planning
- ▶ Problems consistent within and across networks
- ▶ Tailor recruitment strategies to communities served by the network including strategies for reaching families and special communities
- ▶ Essential to build and sustain strong relationships with stakeholders
  - With broad stakeholder groups for recruitment
  - With study volunteers for retention



# Major Questions and Issues Raised

- ▶ How to engage referring physicians and health providers?
- ▶ Where can we find practical tips on the use of media (e.g., print and the Internet)?
- ▶ What strategies and approaches work best among hard-to-reach populations?



## Major Questions and Issues Raised (...continued)

- ▶ How to determine whether recruitment in a small disease population has reached the saturation point?
- ▶ How do we standardize recruitment and retention effectiveness for comparisons between sites within a network and across networks?
- ▶ What are the best metrics to gather to effectively manage recruitment and retention strategies?



# IECRN Examples of Best Practices

- ▶ Five common techniques were identified for ensuring participants were enrolled and retained in clinical studies
  - Establish a partnership with the affected community
    - E.g., HSG
  - Ensure research offers a win-win scenario
    - E.g., RUPP-AN
  - Work with local experts to develop recruiting strategies
    - E.g., CDN
  - Adapt the recruitment strategy to the local context
    - E.g., EMNet
  - Take advantage of economies of scale
    - » E.g., NCRN



# Discussion Takeaways

- ▶ Overall – No surprises in the report; Too general and anecdotal; Limited discussion of challenges; But, a good beginning...
- ▶ Highlights the need for:
  - Quantitative metrics on strategies and approaches utilized and their effectiveness
  - Guidelines and standardized, proven strategies and approaches to export across the network
  - Opportunities to share successful strategies and practices



## Next Step Ideas Raised

- ▶ Establish working group or ongoing forum to share successful practices and valuable resources
- ▶ Spend time reviewing IECRN's online profiles of networks and their practices
  - Identify valuable ways to expand profiles
- ▶ Lessons to be learned from private sector networks and investigative sites



## Next Step Ideas Raised (...continued)

- ▶ Develop clearinghouse for recruitment and retention resources and templates that can be repurposed
- ▶ Create ‘out-of-the-box’ incentives to attract volunteers
  - Tax credit or tax waiver for study volunteers
  - Convenience enhancers (e.g., Drive through sample drop off)

