Interview Guide

INTRODUCTION (5 min)

Thank you very much for agreeing to participate in this interview. The aim of the interview is to gather your opinions, perspectives, and recommendations on advancing research in childhood-onset lupus (cSLE), pertaining to improved diagnosis, treatments and quality of life. We are interested in identifying gaps in knowledge and necessary next steps for advancing lupus care. Last year a survey was conducted jointly by CARRA (Childhood Arthritis and Rheumatology Research Alliance) and the LFA (Lupus Foundation of America), as an initial step to identify high priority research areas in cSLE. To gain more in-depth perspective, we are now conducting interviews with people like yourself who have expertise in various aspects of cSLE care and research. Your insight will help to develop create a roadmap for cSLE research, for use by the lupus community including researchers, clinicians, patients and families, foundations, industry and policy-makers and government agencies.

    Just a few reminders about the interview:
- *It will be audio-recorded so that your comments will be accurately captured during our discussion.*
- *We expect the interview to last approximately 30 minutes.*
- *No statements or opinions expressed during your interview will be specifically attributed to you.*
- *You are not required to answer all of the questions; you may pass on any question you do not wish to answer.*
- *Your participation is voluntary, you can stop the interview and your participation at any time.*

Do you consent to participate in this interview?
Yes   No

Do you consent to be audio-recorded during this interview?
Yes   No

Supplemental material

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MAIN INTERVIEW QUESTIONS

A. Identifying research priority areas in cSLE

1. In your opinion, what advancements have you seen in cSLE research in the last 10-20 years?

2. What do you see as the biggest knowledge gap in cSLE?

3. What in your opinion are the highest priority areas for current cSLE research (top 3)?

   - Are there particular disease manifestations that you would identify as high priority?
     - eg. nephritis, neuropsychiatric, skin, cardiac, anti-phospholipid syndrome, arthritis, hematologic
   - Are there particular disease comorbidities that you would identify as high priority?
     - eg. mental, reproductive, cardiovascular, bone
   - Are there particular health care access and utilization issues that you would identify as high priority?
     - eg. disparities, transition, care coordination

4. What in your opinion are the highest priority areas for <u>future</u> cSLE research (top 3)?

B. Identifying approaches for high priority research areas in cSLE

1. You identified (blank) area as high priority for current cSLE research. I would like to discuss your thoughts on which type of research approaches (for example: epidemiology,

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observational, comparative effectiveness, clinical trials, basic science) are needed to address (blank). Are there any ways you have been in involved with multidisciplinary research in cSLE? (If needed, probe: how familiar do you feel with it). In your view, how would you describe the role of multidisciplinary research in cSLE?

2. Have you been involved in cSLE research using patient-reported outcomes? (If needed, probe: how familiar do you feel with it). In your view, how would you describe the role of patient-reported outcomes in cSLE research?

3. Are there any ways you have been in involved with patient-engaged research in cSLE? (If needed, probe: how familiar do you feel with it). In your view, how would you describe the role of patient-engaged research in cSLE? Are there ways that we can better engage patients and parents in research?

4. What role do you think implementation science (defined as study of methods to promote integration of evidence based medicine and interventions into healthcare) has in cSLE research?

5. What role do you think quality improvement (defined as systematic continuous actions for measurable improvement in healthcare) has in cSLE research?

6. If you could give $10 million to cSLE research, is there a type of project that you think would have the biggest impact?

C. **Identifying barriers and facilitators for cSLE research**

1. You mentioned (sequentially restate high priority areas) as being high priority research areas, what barriers do you see in addressing these areas (sequentially discuss barriers to each area identified)?

   - Are there examples of significant barriers that you or others you know have encountered?

   - What are the significant barriers for investigators in general?

     o Investigators – supply of new investigators, quality of research skills, longevity in research

     o Collaboration – within and among pediatric rheumatology research organizations (eg. CARRA, PRES, PRINTO, others?), general rheumatology organizations (ACR, EULAR), multidisciplinary partnerships

     o Patients – numbers, recruitment/enrollment, retention

     o Funding – availability, amount, duration/sustainability

     o Knowledge dissemination & translation

2. What are the key steps for improving cSLE research?

   - Are there examples that you have seen work well?

   - What solutions would you pose for overcoming barriers related to aspects of cSLE research?

     o Investigators

     o Collaboration

     o Patients

      o   Funding

      o   Knowledge dissemination & translation

CLOSING

The aim of today's focus group was to discuss ways to advance cSLE research. As we end today's interview, is there anything we may have missed?

Thank you for taking the time to participate in the interview. We truly value your perspective on research in cSLE. We look forward to sharing the aggregated results with you.