

Objectives

- Systemic Lupus Erythematosus (SLE) primarily affects females of reproductive age. Despite improvements in clinical care, people with SLE still report informational needs regarding pregnancy.
- To inform obstetric rheumatology service development, this study sought to better understand the reproductive informational needs of people with SLE.

Results

- Ninety-one respondents with SLE (aged 18-49) met inclusion criteria; 70/91 (77%) had experienced pregnancy, and 21/91 (23%) were currently considering pregnancy.
- Respondents rated the importance of knowing about the following topics (presented from most-least important by respondents) in Figure A.
- There were 47/91 participants who shared where they currently get such SLE pregnancy information from. The most cited source was their doctor in 20/47 (40%), followed by the charity Lupus UK in 18/47 (38%), Google search engine in 18/47 (38%), other health care professionals in 6/47 (13%) followed by support groups 4/47 (9%) and scientific journals 4/47 (9%).

Methods

- An online survey was piloted and distributed in University College London Hospital clinic and Lupus UK social media channels (August–September 2025). Inclusion criteria were females aged 18–49 who were pregnant, previously pregnant or considering pregnancy.
- Analysis was via 5-point Likert scale (from Very important-Not very important) assessing importance to respondent (separate questions relating to research priorities were analysed in parallel work).

Conclusions

- Females planning pregnancy with SLE place high importance on having more information on medication safety, how SLE may affect their baby and pregnancy, but also about physical therapy, day-to-day coping strategies and sources of emotional support. Information for family and workplace were also valued.
- These findings highlight the need for holistic, patient-informed approaches to SLE pregnancy care, ensuring both physical and psychosocial domains are addressed.

Figure A: Importance of SLE pregnancy care topics as rated by UK females living with SLE with experience of or considering pregnancy (n=91)

