disease duration (SD) 9.3 years (8.1). A total of 195 flares occurred in 76 patients over 781 monthly assessments, giving a flare rate of 0.25/month. There were 37 severe flares (22 patients), 32 moderate flares (19 patients) and 126 mild flares (67 patients) [Table 1]. The median time to any “A” or “B” flare was 4 months (95% CI 2.7 to 5.3 months). Figure 1 shows the time to the first mild/moderate/severe flare (Curve 1), moderate/severe flare (Curve 2) and severe flare (Curve 3). Table 2 shows that severe and moderate flares tend to be in the system/s affected at baseline whereas mild flares are more likely to affect any system.

Conclusions This real world cohort will share similarities with populations recruited to clinical studies so these results may inform future trial design.

Background and aims Patients with CLE may experience symptoms, which can negatively impact their quality of life. The objectives of this study were as follows: 1) to investigate patient experiences associated with CLE, 2) to investigate the impact of living with CLE on patients’ lives, 3) to evaluate the content validity of the 36-item Short Form Health Survey (SF-36) and the Skindex-29+3 PRO instruments in the CLE population, and 4) to evaluate the appropriateness of a shorter recall period of 1 week instead of 4 weeks for the Skindex-29+3.

Methods This cross-sectional qualitative study utilised a combined concept elicitation (CE) and cognitive interview (CI) method. Study participants were recruited across three US clinical sites and interviewed one-on-one during a 90 min in-person interview. Interviews followed a semi-structured interview guide that elicited patient experiences with CLE and its impact on patients’ lives, followed by CI that assessed patients’ understanding and interpretation of each instrument.

Results Patients found these instruments to be readily understandable, interpreting items correctly and with minimal difficulty. Patients reported a one-week recall period for the Skindex-29+3 to be meaningful and easy to use, although many stated that their symptoms and experiences were felt over a longer period of time.
Conclusions: The majority of instruments’ items were confirmed to be meaningful, interpretable, and appropriate for use in the CLE patient population. The results of the interviews support the content validity of the SF-36 and Skindex-29+3 in the CLE patient population.