Background and objectives Paediatric ILD is rare, so even clinicians in large centres will see very few cases. We aimed to report the experience of parents of children diagnosed with ILD in order to inform current clinical practice, and future planning of health care.

Methods Between February 2014 and March 2014, UK based families with children given a diagnosis of ILD completed an anonymous comprehensive web-based survey developed by the chILD Lung Foundation. The survey consisted of mainly closed questions, with some open qualitative questions.

Results Of the 37 families who completed the questionnaire, 70% of participants reported that they were very happy/happy with the overall management of their child. Diagnoses: unknown 38% (n = 14), neuroendocrine hyperplasia of infancy 16% (n = 6), ABCA3 mutations 8% (n = 3), obliterative bronchiolitis (OB) 24% (n = 9), follicular bronchiolitis 3% (n = 1), pulmonary interstitial glycogenosis 3% (n = 1), surfactant protein C mutations (SP-C) 5% (n = 2) and chronic bronchiolitis 3% (n = 1). Median age at diagnosis was 35 weeks (range 1 week to 8 years), with 25 weeks the median time from first symptoms to diagnosis (range 1 week to 8 years). Areas of concern were (a) communication; care plans/treatment strategies were provided by a respiratory consultant in only 19 of 37 cases, (b) written information; care plans/treatment strategies were provided by a respiratory consultant in only 19 of 37 cases, (c) psychological services were reported as offered to 25 of 37 families, (d) feeding issues; reported by 77% of families (which is not a feature of ILD described in the literature) and these persisted in 35%, mostly long-term gastrostomy dependency and oral aversion. Qualitative responses included requests for better written communication between hospitals and training for smaller hospitals, and improved specialist nurse support of children with ILD.

Conclusion These data provide a broader understanding of parent experiences and perspectives, which should be important now for professionals looking after children with ILD as well as for those planning of future services.

**Abstract P99 Figure 1** Bland-Altman comparison of LCI and FRC between MBW devices. Limits of agreement not shown as variability of the differences are proportional to mean values.