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**Title:** Factors affecting quality of life in children, adolescents and adults with primary ciliary dyskinesia

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**Body:** Background and objective: Primary Ciliary Dyskinesia (PCD) is a rare autosomal recessive disorder associated with chronic pulmonary disease, rhinosinusitis, serous otitis media and often infertility. We are developing a health-related quality of life (QoL) questionnaire for patients with PCD as an outcome measure. We present data generated during the development of the questionnaire. Methods: Factors affecting QoL in PCD were generated by patients, health-specialists and a literature review. The list of items was sent to members of the UK PCD Support Group, ERS PCD Taskforce and Southampton patients. 100 questionnaires were returned, with items ranked on a Likert scale (1=not at all relevant, 5=very relevant). Mean values for each item were calculated. Semi-structured interviews are being conducted with each age group. Results: The emotional impact of the disease ranked highly for adults and adolescents. For example in adolescents, 'embarrassment from having a runny nose' had the highest mean score (4.11), whilst 'physical problems from symptoms of PCD' was less of an issue (2.56). Lack of understanding about PCD by others was highly relevant for all age groups, but particularly children, whose classmates did not understand (4.43). PCD was reported to have little impact on social life in at all ages. Conclusions: Patients of all age groups reported emotional consequences and embarrassment from PCD. Adults reported physical symptoms to be more relevant than in children or adolescents. The prototype questionnaire with the most relevant items is nearing completion. Cross-sectional and longitudinal validation will be conducted in UK, Ireland and USA.