Comparison of contacts to adult and paediatric cystic fibrosis
Clinical Nurse Specialists

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Introduction: Clinical Nurse Specialists (CNS’s) are commonly the primary point of contact in cystic fibrosis (CF) centres.

Aim: To identify and compare preferred modes of contact to paediatric (P) and adult (A) CF CNS’s for healthcare users. To identify when patients take responsibility for their own management.

Method: P and A CF CNS’s prospectively recorded how, why and by whom they were contacted over a 30 day calendar month. CNS’s were available via telephone and email. The P team have a pager for messaging, A CNS’s have a mobile telephone.

Results: 340 contacts were received (130 P, 210 A) from clinics of 130 P and 147 A patients. Contact methods: phone 57% P vs 75% A, email 12% P vs 7% A. Pager 31% P vs mobile texts 18% A. No children initiated contact in the P clinic. 212 patients <18 years in the A clinic initiated contact. All contacts were from the patients after the age of 18 years. 12 contacts to the P CNS were from Health Care Professionals (e.g. GP, community nurse). Reasons for contact: Respiratory management 42% P vs 39% A. 30% of the A contacts were for administrative issues, e.g. outpatient appointments or admission dates, vs 6% in P. Referral on to other team members was necessary in 12% P vs 21% A.

Conclusions: Patients <18 yrs rarely take responsibility for their own management by contacting their CF CNS, leaving this to parents. Email contact was lower than anticipated in both P and A centres. There was a higher per capita rate of contact from the adult patients 1.4 vs 1, as well as a higher need for further MDT involvement, possibly reflecting their increasing medical needs. This age group utilise technology to contact their CNS’s less than expected.