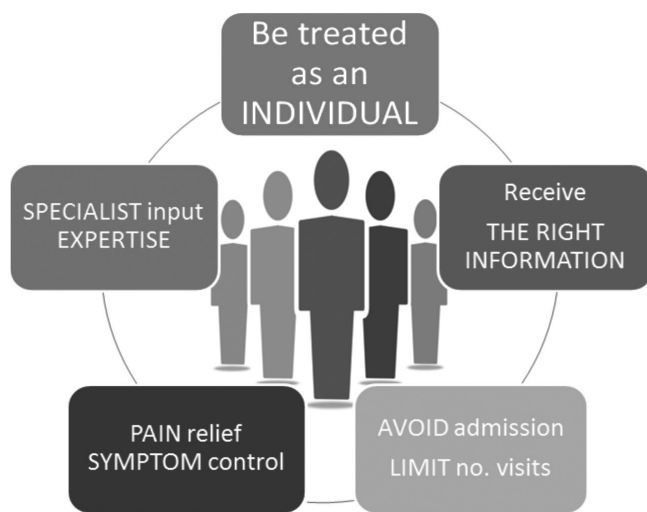


Results 18 patients were surveyed (4 after ascitic procedures), 9 had emotional mapping. The mean overall service rating was 4/5. The graph above represents both responses to the question ‘What is important to you?’ and themes that emerged from emotional mapping.

More detailed insight was gained from the discussion with one patient’s relative, this was triangulated with the other data to give a clearer picture of what was most important to patients. Similar themes were combined to form 5 final patient-centred outcomes that were important to patients (see Figure 1 attached). E.g. ‘Be treated as an INDIVIDUAL’ encompassed good interpersonal relationships and personal choice, and ‘Receive the RIGHT INFORMATION’ for consent, medical care and managing waiting.



Abstract P189 Figure 1

Discussion These five outcomes were developed for a specific service. The data has come from a relatively small number of patients from a specific cohort, but they seem credible, and may be more widely applicable. The next step is to measure the service against these outcomes before and after the. A new patient survey has been designed to measure these outcomes. It will be administered before and after the start of the new service.

Home non-invasive ventilation

P190 DEVELOPMENT OF A RESPIRATORY QUESTION SET FOR REMOTE MONITORING IN MOTOR NEURONE DISEASE (MND)

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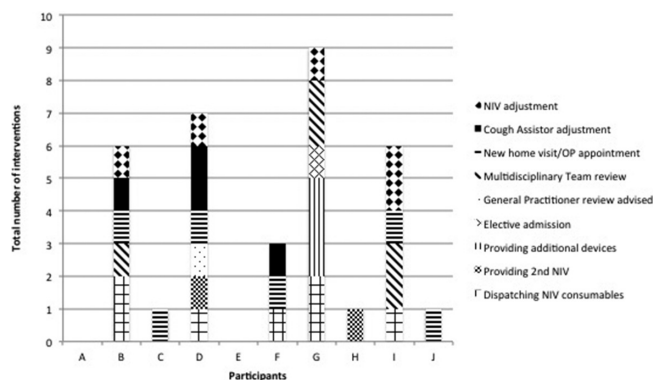
Background Benefits of tele-monitoring (TM) of home non-invasive ventilation (NIV) in MND have been reported. Question sets for other respiratory conditions may not be transferrable. This work sought to develop questions transmitted via tablet device (Dococo Careportal[®]) allowing patients to inform clinicians of respiratory status, illness progression and NIV issues.

Methods Modified Delphi methodology was used involving 4 stages: initial expert panel with clinicians (EP1), trial of

questions and feedback sessions (FS) with patients, second panel with professionals (EP2). 21 questions were developed at EP1 and trialled with 9 patients (male = 7; mean = 58 years; mean illness duration = 52 months) for 8 weeks. FS were conducted after the trial to examine face validity, clarity and relevance. Each question was deemed clear if at least there was 80% agreement. 18 questions were retained, 3 modified, 2 deleted and 5 added. EP2 repeated the process, the resulting final question set contained 26 items of which 17 generate a notification. Patients completed questions weekly, appropriateness of alerts was checked by phone call; the panel specified some notifications to be of greater clinical importance requiring intervention or further observation. It was possible to review reported issues against overnight oximetry and patient ventilation interaction data.

Results For 12 weeks, 10 patients using NIV male = 7; mean (SD) age = 62 (8) years; median illness duration = 16.5 months, completed the final question set weekly. 210 alerts (geometric mean 15.3, IQ range 11–24.) were generated for; sleep quality, alertness, tiredness, NIV compliance, secretion clearance difficulty, increased secretions, and increased dyspnoea. 34 interventions resulted as described in the bar chart: the median number of interventions per patient was 2 (range = 0–9).

Discussion To date the questions appear valid with no misunderstanding revealed. Appropriate and timely treatment adjustment and clinical review was facilitated. Prompt interventions may reduce psychological distress for patients and caregivers. This patient group are normally followed up three-monthly under the current NICE guidance; this question validation work suggests value in more frequent contact. Tele-monitoring, including symptom monitoring with a validated question set, may offer an alternative approach to following these complex patients.



Abstract P190 Figure 1 Bar chart showing total number and type of interventions per participant

P191 SURVIVAL IN PATIENTS WITH CHRONIC TYPE 2 RESPIRATORY FAILURE: A COMPARISON OF OBESITY HYPOVENTILATION SYNDROME, COPD AND OVERLAP SYNDROME

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Introduction and objectives Home non-invasive ventilation (NIV) is established for the treatment for patients with obesity-related type 2 respiratory failure. Long-term outcomes for the use of NIV in patients with chronic hypercapnic COPD and “overlap syndrome” are less certain. Our objective was to