WS05.1 The development of a website to facilitate transition from paediatric to adult CF services

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Many children with complex long term conditions now survive into adult life as a result of advances in medical technology and treatments. This is particularly true in Cystic Fibrosis where the UK median predicted survival was 36.6 years in 2013. One facet of an effective transition is the provision of age appropriate and accessible information. Recent research in transitional care programmes has highlighted that communication and information resource methods are changing, identifying that young people embrace the use of technology to understand their condition and improve their self-management skills. We conducted a survey of our young patients, asking them their views on the development of transition services. They confirmed the importance of access to web based information on a variety of platforms. We involved this same group in the development of a website aimed at improving access to high quality information regarding our hospital, its services and some of the commonly encountered practical and psychosocial issues surrounding transition. This website provides video and text based information, delivered by patients, relatives and health care professionals in an engaging and immediately accessible way. It has received excellent feedback and is frequently accessed by our patients. Furthermore it has assisted with the difficult problem of providing effective transition in the context of the need for microbiological segregation. We present our development process and completed website as a model for use by other CF centres.

WS05.2 30 day challenge − using social media to support adult CF patients to exercise in the adult CF service Dundee

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Objectives: To use social media as a medium to encourage CF patients to exercise and support each other.
Methods: Ten patients already using Facebook regularly signed up to the 30 day challenge in November 2014. The challenge consisted of a daily increase in number of squats, press ups and sit ups with every fourth day a rest day. A closed group was set up on Facebook with access only for patients and staff. The patients were encouraged to post entries regarding progress and any barriers faced.
Results: One patient stopped the challenged due to a prolonged hospital admission. One patient did not use his Facebook account but partially completed the challenge. Seven patients almost fully completed the challenge. Up to nine patients viewed the posts by staff with three of them regularly posting comments. Five of the patients found using Facebook kept them motivated to continue with the challenge and to try and encourage others.
Conclusion: This was a small pilot study using social media. As half the patients found it maintained their motivation to exercise we will roll this out to more patients in 2015 trying four challenges. We are also working with the paediatric physiotherapy team to include families of children with CF for the new challenges.

WS05.3 Sleep architecture in CF patients as assessed by the Body Media's SenseWear® Armband (SWA)

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Background: Many CF patients complain of altered sleep quality and, in some of them, polysomnography shows sleep disorders with frequent awakenings, night cough, lower sleep efficiency (SE) and less REM sleep. The SWA, which measures body movement, surface body temperature, galvanic and heat flux skin response, proposes a non-invasive and simple way to measure sleep stages at home.
Objectives: Our study
1. examined the validity of SWA to detect sleep stages in normal controls compared to published normative values (Ohayon et al, Sleep 2004) and
2. compared SWA-derived sleep architecture between normal controls and stable CF patients.

Methods: 15 CF adults (31.6±12.3 yrs; FEV_1 65.5±24.4% pred) and 19 CF children (10.5±3.4 yrs; FEV_1 83±13.4%) were compared with 13 healthy adults (32.3±11.5 yrs) and 11 healthy children (10±1.9 yrs). CF patients and healthy subjects wore the SWA for an average of 5 and 2 nights, respectively. Light sleep (LS, stages 1 and 2), deep sleep (DS, stages 3 and 4); REM stage and SE were evaluated as the % of total sleep time.
Results: In healthy subjects, SWA showed SE and DS measures consistent with published normative values whereas LS and REM seemed to be over- and under-estimated, respectively. In CF adults, but not in CF children, SE was lower when compared to normal controls (adults: 77.3±8.5% vs 86.3±4.7%; $p = 0.003$; children: 81.0.3±6.8% vs 84.4±5.0%; $p = 0.154$). None of the sleep stages differed between patients and controls, except for REM sleep which was lower in CF children.
Conclusion: SWA is a simple and promising method to detect sleep architecture disorders in CF patients, notably sleep efficiency.

WS05.4 Video games for positive expiratory pressure (PEP) therapy in children with cystic fibrosis: a pilot study

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Background: Adherence to respiratory physiotherapy is a major challenge in children with cystic fibrosis (CF). Video games have shown promising results in improving adherence to treatment in chronic diseases. However, the feasibility of adapting video games to positive expiratory pressure (PEP) therapy in CF has not been explored.
Hypothesis: Therapeutic games can be adapted to PEP therapy.
Methods: In collaboration with students in the game design program of University of Montreal, we developed and adapted 3 video games to the parameters of PEP therapy (6 series of 15 respirations). The PARI's PEP S™ device was connected to a computer by a pressure sensor. Ten children (5 girls, 5 boys) between the age of 8 and 10 tested the video games on one occasion during PEP therapy under the supervision of the physical therapist of the CHU Sainte-Justine CF clinic. Questionnaires were completed before and after the trial by all participants which consisted of their overall evaluation of the games, their interest in pursuing the video games at home and whether they believe the games may improve adherence to PEP therapy.
Results: The PARI's PEP S™ device was successfully connected to a computer and all PEP parameters were monitored adequately. Nine children (9/10) were very interested in pursuing the video games while doing their PEP therapy at home. All of them thought that the games were well adapted to the PEP therapy and that it may improve their adherence to the treatment.
Conclusion: Video games can be adapted to PEP therapy. A second study is currently being planned to investigate whether video games may improve adherence to respiratory physiotherapy in children with CF.

WS05.5 Developing an audio-visual intervention to support children's adherence to home chest physiotherapy for cystic fibrosis

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Objectives: To develop and test an audio-visual supportive intervention to improve adherence to home chest physiotherapy among young children aged 0–8 years with cystic fibrosis (CF) and their parents. Adherence is important because lung damage occurs rapidly and can be irreversible. However, only 50% of parents and young children adhere to their recommended physiotherapy regimen. Interventions to address this significant problem are lacking.
Methods: We co-developed a theory-informed film and adherence plan over 8 months with a purposively recruited online group of 14 parents of 13 children aged 0.5 to 8.5 years and 8 NHS clinicians in the UK. We qualitatively analysed data to identify parent preferences for the intervention, barriers and solutions to adherence, and parents' use of behaviour change techniques (BCTs). Clinicians ratified parents' solutions.
Results: There are parent, child, and societal/ external barriers to physiotherapy adherence. Many, but not all, of parents' solutions correspond to known BCTs e.g. distraction and habit formation. Parents wanted a family film to convey ways to make physiotherapy more enjoyable and to explain to children the need for physiotherapy. Our film incorporates BCTs into an entertaining narrative featuring real families and cartoon-style animation to motivate parents and suggest strategies to encourage adherence. We are now feasibility testing the intervention.
Conclusion: After a future full-scale trial, this resource could help increase physiotherapy adherence in young children with CF and so decrease the likelihood of lung damage and medical complications, reducing health burden and costs to families and the NHS.

WS05.6 A pilot study of enhanced community support via internet videoconferencing and physiotherapist home visits

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Objectives: Specialist centre care only is recommended for all UK Adult CF patients. Many patients face long journeys to attend the centre. This may lead to poor attendance and engagement. We evaluated the feasibility and effect of regular patient contact at home via videoconferencing and home visits from CF physios in selected patients with a history of poor engagement with and long journey time to the centre.
Methods: 20 patients were invited to take part. Study patients were supplied with a laptop and webcam and Cisco Movi secure videoconferencing software. Weekly contact via video and monthly home visits were planned for 6 months. Outcomes were assessed by a patient satisfaction survey and regular FEV_1, CFQ-R scores and weight.
Results: 6 patients agreed to take part and 5 completed follow up. Videoconferencing was frequently unsuccessful due to poor rural broadband speeds, ICT support and patient engagement. Patients satisfaction was high for both videoconferencing and home visits with perception of improved health and treatment concordance. Home visits were felt to be of greatest benefit. 2 patients saw significant improvements in FEV_1 and weight. Staff perception of concordance improved in 3 patients. CFQ-R scores did not show consistent trends in any domain.
Conclusion: Uptake of free enhanced home support was low in patients with a history of poor engagement, living in remote locations and is not a panacea for this problem. Rural broadband speeds are often inadequate to support videoconferencing. In selected patients internet video support and home visits can successfully augment usual care with objective and subjective benefits and is rated highly by patients.