

Psychological Care and Service Provision for Children and Young People within Paediatric Respiratory Services in the United Kingdom

Good Practice Guidance
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This guidance refers to the work of practitioner psychologists. Practitioner psychologists work under protected titles which include Clinical and Counselling Psychologists and are regulated by the Health and Care Professions Council. The authors recognise that many professionals with psychosocial expertise work in paediatric services across the UK and that the psychological needs of children and young people under the care of paediatric respiratory services and their families are multifaceted and will be best met by a range of professionals.

Contents

1. Executive summary	5
2. National context	6
3. The rationale for psychological provision in paediatric respiratory services .	8
3.1 Asthma	8
3.2 Long-term ventilation (LTV)	10
3.3 Primary ciliary dyskinesia (PCD)	13
3.4 Children and young people with neurodisability	14
4. The work of practitioner psychologists in paediatric respiratory services ...	15
4.1 An integrated approach	15
4.2 A stepped-care approach.....	15
4.2.1 Universal support.....	16
4.2.2 Targeted support	18
4.2.3 Clinical support	20
4.3 Other roles of the practitioner psychologist	22
4.3.1 Leadership	22
4.3.2 Teaching and training.....	23
4.3.3 Management, recruitment, policy and service development	23
4.3.4 Research and service evaluation.....	23
5. Service provision and development	23
6. References	26
7. Appendix.....	30
7.1. Summary of key recommendations from national respiratory guidelines and quality standards relevant to paediatric psychology	30
7.2 Summary of key recommendations from national respiratory guidelines and quality standards relevant to paediatric psychology	31
7.3 Summary of roles and responsibilities of practitioner psychologists	32

1. Executive summary

Paediatric respiratory services within the UK have seen a dramatic rise in the number of children and young people under their care in the last decade (RCPCH, 2020). Research demonstrates that children and young people with physical health conditions experience significantly more emotional distress than their healthy peers (Mercer, O'Curry, Stedmon, Reed & Griggs, 2015) and that living with a physical health condition has outcomes for a child or young person's psychosocial development, education, family relationships and reaching age-related developmental tasks, which can impact the trajectory of illness and modulate the effectiveness of medical treatments and interventions. Difficulties with adherence to medical regimens and treatments, poor self-care, difficult relationships with friends and family, challenges in attending school regularly and sadness and worry about the future are all examples of the way emotional distress may present itself for children and young people (Christie, 2020). Accordingly, the importance of effective, timely and accessible psychological support for children and young people with physical health conditions and their families is now recognised (Mercer et al., 2015) and practitioner psychologists are being increasingly cited as key members of the paediatric medical team.

Children and young people under the care of paediatric respiratory services have a range of respiratory conditions including, but not limited to: asthma, bronchiectasis, cystic fibrosis, congenital respiratory conditions, interstitial lung-disease and PCD; a proportion of this population require non-invasive (NIV) and/or long-term ventilation (LTV). An obvious omission from this guidance is work with children and young people with cystic fibrosis. Psychological provision for this group of children and young people has been embedded in national and international standards for some time and the landscape of diagnosis and treatment for children and young people with CF is rapidly changing. We therefore encourage readers to refer to the most recent guidance in this area produced by the European Cystic Fibrosis Society in 2018 (Castellani, Duff, Bell et al., 2018). Instead, this document places focus on work with children and young people under the care of paediatric respiratory services more broadly and with specific reference to working with children and young people with difficult (to treat) asthma, PCD, children with neurodisability and those requiring long-term ventilation.

This guidance provides a rationale and evidence base for the role of practitioner psychologists working with children under the care of paediatric respiratory teams and their families. It provides recommendations for psychological provision and

models for service delivery to guide service leads and inform service commissioning. It presents recommendations for minimum staffing levels for practitioner psychologists agreed by the Paediatric Respiratory Psychologist Specialist Interest Group (Table E1).

Table E1. Proposed minimum practitioner psychologist staffing levels (other than CF)

Area of Work	Wte	Clinic size
Long-term ventilation	0.5 (8a)	75
Difficult asthma	0.5 (8a)	100
PCD	0.55 (8a)	150
General respiratory*	0.5 (8a)	150

**Including children with a neurodisability*

2. National context

This document originated from a call to action on psychological ways of working within paediatric respiratory services from the UK Paediatric Psychology Network (PPN) and discussions between members of the Paediatric Psychology Respiratory Special Interest Group established in 2017.

Initial discussions and a subsequent service mapping exercise highlighted the highly variable nature of psychological provision within paediatric respiratory services across the UK, with considerable differences in the availability of paediatric psychology between services and regions. This is particularly concerning when compared with psychological provision in areas such as cystic fibrosis and diabetes which, in comparison, have recommendations for the provision of paediatric psychology embedded within national and international standards (Castellani, Duff, Bell, et al., 2018; NICE, 2016), albeit also poorly resourced.

Over the last decade, paediatric respiratory services have seen a dramatic rise in the number of children and young people under their care, with the UK currently having one of the highest prevalence, emergency admission and death rates for childhood asthma in Europe (Fine-Gouldon, Ray & Brierley, 2015; RCPCH, 2020). Additionally, clinical advances in neonatal and paediatric intensive care alongside technological advances in mechanical ventilation has meant that many more children who need either temporary or permanent ventilator assistance are surviving

(RCPCH, 2020) and an increasing proportion of these young people are now transitioning to adult care services (Wallis, Paton, Beaton & Jardine, 2011).

Paediatric psychology is an area of clinical practice and research that is concerned with the relationship between children's psychological and physical well-being, with practitioner psychologists working in this area focusing on the emotional, behavioural and social impact of disease and illness for children, young people and their families. Given the increasing demand on paediatric respiratory services and the well-recognised role that practitioner psychologists play in supporting paediatric populations, we hope this document proves to be a useful and timely tool for practitioner psychologists working directly with families, our colleagues in the wider multi-disciplinary respiratory team and those involved in leading and commissioning services. This guidance presents up-to-date evidence-based practice, research and clinical expertise pertaining to the psychological needs of children and young people with long-term respiratory conditions and their families. It aims to illustrate why it is essential that this population of children should have access to psychological provision at a consistent standard, regardless of geographical location, and refers to the work currently being undertaken by practitioner psychologists working in paediatric respiratory services across the UK. Finally, recommendations are made regarding psychological provision to inform service commissioning and minimum staffing levels for practitioner psychologists.

Children and young people under the care of paediatric respiratory services have a range of respiratory conditions including, but not limited to: asthma, bronchiectasis, cystic fibrosis, congenital respiratory conditions, interstitial lung-disease and PCD; and a proportion of this population require non-invasive (NIV) and/or long-term ventilation (LTV). An obvious omission from this guidance is work with children and young people with cystic fibrosis. Psychological provision for this group of children and young people has been embedded in national standards for some time (CF Trust, 2011) and the landscape of diagnosis and treatment for children and young people with CF is rapidly changing. We therefore encourage readers to refer to the most recent guidance in this area produced by the European Cystic Fibrosis Society in 2018 (Castellani, Duff, Bell et al., 2018). Instead, this document places focus on work with children and young people under the care of paediatric respiratory services more broadly and with specific reference to working with children and young people with difficult (to treat) asthma, PCD, children with neurodisability and those requiring long-term ventilation. It is important to emphasise that much of what is described in terms of paediatric psychology provision is not limited to work with these specific populations and will be relevant to the wider

population of children and young people under the care of paediatric respiratory services.

3. The rationale for psychological provision in paediatric respiratory services

Every child, young person and family will respond differently to the challenges of living with a physical health condition, based on their experiences of health and health care systems, personality, family and social relationships, culture, religious and spiritual beliefs, and ways of coping. It is crucial that paediatric respiratory services make efforts to understand the experiences which a child and family brings with them and how these experiences influence adjustment and coping (Mercer et al., 2015) and that there is timely access to practitioner psychologists specialised in supporting children and families when difficulties arise.

3.1 Asthma

Asthma is the most common long-term condition of childhood (Boyd, Lasserson, McKean, Gibson, Ducharme & Haby, 2009; WHO, 2021) and in the UK is the leading cause of paediatric hospital admissions (Asthma UK, 2018). When poorly controlled, asthma can affect almost every aspect of a child's daily life including participation in sports, attending school and relationships with family and friends. Children with poorly controlled asthma are at an increased risk of acute asthma attacks, which increases their likelihood of experiencing a range of negative physical, emotional and educational consequences (von Mutius et al., 2000; WHO, 2021).

Once considered a single, though complex, disease, asthma is now recognised as a multifaceted spectrum of conditions where genetic and environmental factors play a role in airway inflammation and hyper-reactivity. The label of difficult (to control) asthma is given when symptoms are not well-controlled by high-dose inhaled controller medications and children experience two or more asthma exacerbations in a 12-month span requiring oral corticosteroids.

Children and young people who have difficult asthma experience restrictions upon their activities, and frequent and severe exacerbations of asthma symptoms often require intensive care admissions. Usual forms of asthma treatment may not be as effective for these individuals and these young people often have co-morbid diagnoses including allergic rhinitis, gastroesophageal reflux, obesity or immune deficiency (Asthma UK, 2018; Bousquet et al., 2010; Chung et al., 2014; Papi, Brightling, Pedersen & Reddel, 2018).

It is well established that children living with difficult asthma are at an increased risk of experiencing psychological symptoms, such as anxiety, depression, increased stress and panic symptoms (Licari, Ciprandi, Marseglia, & Ciprandi, 2019; Lawson, Rennie, Dyck, Cockcroft, & Afanasieva, 2017; Selby et al., 2018). In turn, research demonstrates that psychological distress can exacerbate asthma (Sharrad, Sanwo, Carson-Chahhoud & Pike, 2019) and is associated with an increased reporting of asthma symptoms (Richardson et al., 2006). Consequently, psychological factors are included in definitions of difficult asthma and are recognised as adding further complexity to its management (Oland, Booster & Bender, 2017).

Referrals to psychology are often made for children requiring support with treatment adherence, managing anxiety, feelings of difference and coping with difficult medical experiences such as PICU admissions. A substantial proportion of children and young people experience interactions between asthma symptoms, breathlessness and anxiety (Oland et al., 2017) and difficulties can arise in differentiating between asthma symptoms and the physical symptoms of anxiety such as hyperventilation, breathlessness, sweating and shaking (see Figure 1). For these children, the physical manifestations of anxiety can be mistaken for uncontrolled asthma and managed by inappropriate escalation of medication and attendance at A&E. Fearful thoughts connected with this state such as 'I can't breathe', or 'I'm going to die' in turn fuel the anxiety response. In this way, the consequences of anxiety can complicate the clinical picture and lead to repeated hospital admissions and escalation of medical interventions that could be avoided with early recognition and treatment.

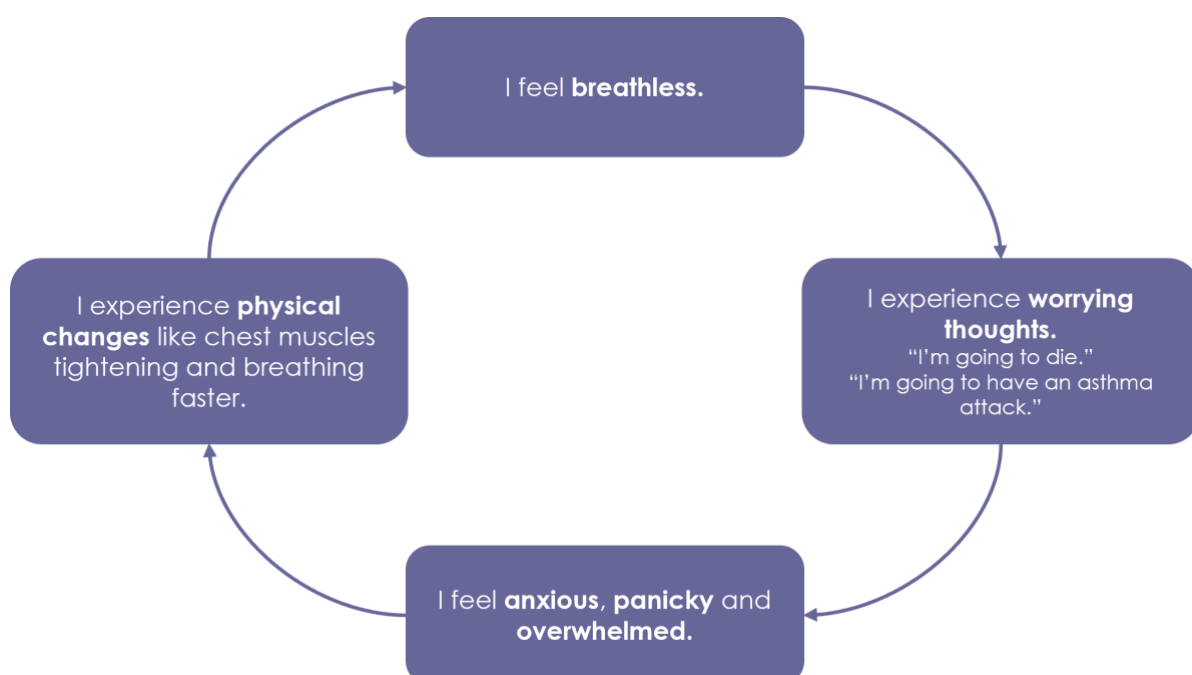


Figure 1: CBT-informed cycle describing the interaction between asthma symptoms, cognitions and emotions

Children seen by asthma services should be thought about in the context of the family and wider social system which surrounds them. Parents and family members often have had to tolerate high levels of uncertainty, to monitor and ensure adherence to intensive medical regimes or may have had to navigate sudden and unexpected – sometimes life-threatening – hospital admissions. It is widely reported that there is a higher incidence of anxiety and depression in parents of children with asthma (Easter, Sharpe & Hunt, 2015) and that where there has been a life-threatening event and/or an intensive care admission, emotional difficulties may be compounded by trauma responses in both the child and the broader family (Millikan Kean, Kelsay, Wamboldt & Wamboldt, 2006).

In terms of their wider social network, it is well documented that children with asthma have higher levels of school absenteeism than their healthy peers which can have implications for academic performance, peer relationships and future attainment (Fleming et al., 2019). Practitioner psychologists can play a key role in liaising with schools to provide information on the psychological impact of asthma in childhood and to share individual formulations to help schools optimise the child or young person's ability to access education.

Finally, although asthma can affect children of any age and background, it is crucial to recognise that asthma is most prevalent within more deprived communities. Children living in the most deprived communities are more likely to experience a hospital admission for asthma (Asthma UK, 2018) and are more likely to encounter triggers for asthma, including air pollution. In this way, a family's efforts to effectively adhere to treatments may be negated by socio-economic deprivation and the environment within which they live as well as their access to healthcare. Such inequalities in the early years have life-long impacts for both the physical and emotional health of individuals and of society (Marmot, Allen, Boyce, Goldblatt & Morrison, 2020). It is therefore vital to have interventions aimed at supporting children and young people to better adhere to treatments and engage with healthcare systems, as well as action on the part of healthcare professionals – including practitioner psychologists – to raise awareness of and reduce health inequalities.

3.2 Long-term ventilation (LTV)

Long-term ventilation describes a range of treatments used to support individuals who require mechanical aids for breathing, either invasively by tracheostomy or

non-invasively (via a mask), for all or part of a 24-hour day (Wallis et al., 2011). The population of children and young people seen by LTV services is diverse, ranging from babies born prematurely and infants receiving perinatal diagnoses to older children with reduced respiratory or neuromuscular function (NCEPOD, 2020). A significant proportion of young people seen by LTV services have multiple co-morbidities and complex developmental and communication needs and may be under the care of multiple paediatric teams including (but not exclusive to) respiratory, neurodisability, neurology and oncology. As a result, long-term ventilation is utilised in different ways; for some children it can be used as a 'bridge to recovery', helping to sustain a child while growth and recovery occur, whilst for others it may be a 'destination treatment' helping children with an incurable condition return home (Brookes, 2019).

Practitioner psychologists have only recently been identified as key members of the LTV team and consequently there is a paucity of research exploring the psychological factors for this group of children. However, we can extrapolate from the guidance and evidence base from similar paediatric conditions which require a high level of treatment, medication and technology dependence, such as cystic fibrosis, as well as from the knowledge gained from our own clinical practice.

Psychological work with this patient group is multifaceted and may involve work with the individual child, the child's family or the systems around the child, including medical and care teams.

Young people with LTV and their families are likely to require psychological support at several points through their healthcare journey, including involvement with understanding and adjusting to a new diagnosis and the concept of LTV, through to the establishment of LTV care in hospital, transitions from intensive care and wards to discharge home and finally continued support while using LTV at home (see Figure 2). Every family's journey is different and psychological support will be beneficial at different points throughout this journey, depending on the needs of the individual family.

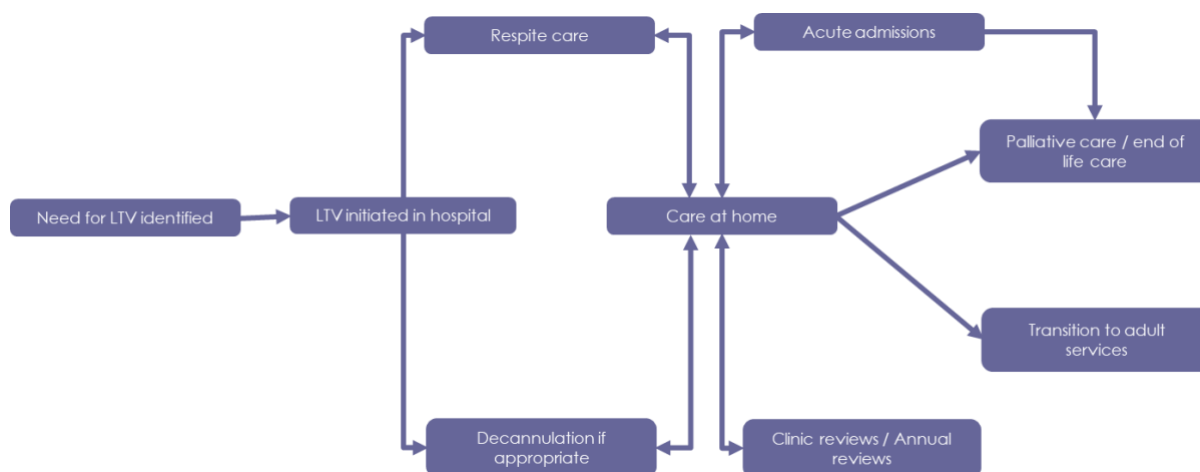


Figure 2. The LTV journey. Adapted from Patient Experience Network (2014) and NCEPOD (2020)

The need for LTV often arises in inpatient settings from an early age and LTV initiation is frequently part of a stormy medical journey to gain an understanding and diagnosis. Work within inpatient settings is largely based on the needs of the family and sessions are often focused on providing containment for the family, counselling support and being an advocate during medical meetings. Families of infants initiated to LTV, particularly those invasively ventilated, often experience extended hospital admissions resulting in separation and isolation from the rest of their family and other support networks. Parents are often in the position of having to make complex decisions about their child's care while getting used to a realm of medical terminology and diagnosis/es and coming to terms with the loss of the child they thought they would have. Feelings of grief, loss and guilt are common, and some families may need time and space to process these reactions as well as the life-limiting nature of the diagnoses. For children with pre-existing life-limiting conditions, initiation onto LTV may represent deterioration of the child's condition and parallel planning with palliative care and respite services is essential to ensuring holistic support for families.

For children, being established onto NIV can be a scary experience as they learn to tolerate ventilation and wearing a mask or nasal probe. Psychological management of fears and previous traumatic experiences of hospital procedures and admissions can all help children, and their families, cope with the hospital stay and/or prevent them cancelling an upcoming admission for NIV initiation. Using NIV requires children and their families to make significant adjustments to their night-time routine and can cause discomfort and disturbed sleep when first introduced. Whilst difficulties adhering to NIV are relatively common (Crawford, Espie, Bartlett and Grunstein,

2014), these need to be addressed in a timely manner to ensure the effectiveness of NIV is not impacted (Amaddeo, Frapin and Fauroux, 2016). A recent study into the experiences of young people requiring NIV identified that non-adherence was associated with both mask discomfort and higher levels of anxiety and depression (Pascoe, Sawnani, Hater, Sketch & Modi, 2019).

Parenting a child who requires LTV will impact parents' and carers' emotional well-being, quality of life, socio-economic status and social connectedness (Lee & Lynn, 2017). Parents are often required to take on intense and complex care in a context where problems and changes to their child's health can be associated with a risk to their child's life (Montagnino & Mauricio, 2004). In addition to their parents and the young people themselves, siblings are likely to be impacted through experiencing changes to their routine and reduced access to parents (particularly during hospital admissions). The experience of having a child within the family requiring LTV has been found to negatively impact siblings' physical and emotional well-being, with some needing to take on additional 'adult' responsibilities within the family home (Bjerregaard Alrø, Klitnæs, Dahl Rossau & Dreyer, 2021). Siblings of children with life-limiting conditions are also at greater risk of developing emotional and behavioural difficulties and experiencing a lower quality of life than their peers (Fullerton, Totsika, Hain & Hastings, 2016). Practitioner psychologists in LTV services have an important role in highlighting the emotional needs of parents and the wider family including that of siblings, providing individual and group-based psychology support.

3.3 Primary ciliary dyskinesia (PCD)

Primary ciliary dyskinesia (PCD) is a chronic autosomal recessive disease which has a reported prevalence of 1 in 10,000–20,000 (Mirra, Werner & Santamaria, 2017) and where problems with the functioning of cilia throughout the body leads to a build-up of mucus causing inflammation and infection in the airways, sinuses and ears. Babies with PCD often present with unexplained neonatal symptoms such as neonatal cough, rhinitis, transient tachypnoea and pneumonia, often requiring respiratory support. Difficulties continue into infancy, with children often experiencing persistent daily symptoms including a wet cough and recurrent chest infections often leading to bronchiectasis. Treatment involves regular clearing of airway mucus, treatment of infections and the management of hearing loss.

Within paediatrics, there is a paucity of research focusing on the psychosocial aspects of living with PCD. In 2017, a systemic review of patients' experiences of living with PCD highlighted declines in self-reported quality of life as children move through adolescence and into adulthood and increased feelings of difference

compared to the general population. Children and teenagers were also found to report feelings of frustration about getting sick regularly and the chronic nature of their symptoms. Anxiety and concerns about future health were also reported, as well as feelings of embarrassment and shame related to their condition, with young people sometimes feeling the need to conceal their diagnosis and/or treatment from others (Behan, Rubbo, Lucas & Galvin, 2017).

Parents and carers of children with PCD also face challenges of caring for a child with a chronic health condition. Parents not only assist children in activities of daily living, but also support their nutritional, physical, social, emotional, medical and financial needs, which has been shown to differentially impact parental well-being (Driessens, Carr, Clough et al., 2022). Practitioner psychologists have a crucial role in working with children, parents and other professionals involved in the care of the child (Schofield & Horobin, 2014) to help minimise the emotional consequences of living with PCD and improve quality of life for children, young people and their families.

3.4 Children and young people with neurodisability

Children and young people with neurodisabilities which result from either congenital or acquired long-term conditions, such as cerebral palsy, often have underlying physiological impairments which place them at increased risk of developing respiratory difficulties; consequently this group of children are frequently seen within general paediatric respiratory clinics.

Many children with neurodisabilities face considerable challenges in their day-to-day life and many are highly dependent on those around them. For example, children and young people with cerebral palsy experience higher rates of challenging behaviour, attention difficulties, social communication problems and mood problems in comparison to the general population. Personal risk factors for psychological distress for this population include cognitive abilities within the normative range, communication problems and less functional disability. Due to their need for higher levels of care and support, a parent's emotional functioning and parenting style can also have a significant influence on a child's development and overall emotional well-being (Rudebeck, 2020). Practitioner psychologists working with this population have an important role in advocating for the emotional needs of these children and young people and the adults who care for them. Work may also include liaising with the significant number of hospital and community services that are often involved and attending multi-disciplinary and multi-agency

meetings to ensure the psychosocial needs of children and their families are kept in mind.

4. The work of practitioner psychologists in paediatric respiratory services

4.1 An integrated approach

Multi-disciplinary team approaches are now seen as the key to the successful delivery of paediatric services. A practitioner psychologist who is embedded in the paediatric respiratory team can provide access to timely specialist assessment and intervention, and facilitate system-wide prevention, early identification and remediation of psychological difficulties. The practitioner psychologist operates a whole-systems approach, not only providing direct assessment and intervention, but working in proactive and preventative ways to promote resilience and enhance emotional well-being. Working within the paediatric respiratory multi-disciplinary team allows the practitioner psychologist to gain a firm grasp of respiratory conditions and the implications for children and their families and avoids the need for them to continually ask patients and families to describe the basics of their condition (Bush, 2011).

4.2 A stepped-care approach

Levels of psychological need inevitably differ between children and their families, as well as within the same family over time, as they navigate their journey from diagnosis onwards. Given these differing levels of need, a stepped-care model to paediatric psychological provision is suggested. The model (see Figure 3) is adapted from a model developed within oncology-focused paediatric psychology services (Kazak, 2006) and presents a framework for assessing and providing intervention for children and families, depending on their level of need and risk.

The 'Universal' level represents preventative input accessible to all families and may include offering resources (e.g., leaflets, booklets) on commonly experienced problems, signposting to other relevant services and screening for psychological difficulties.

The 'Targeted' level includes the provision of short-term individual or group-based interventions, for example to support children in managing difficulties around adherence, providing screening and follow-up for children and parents following an admission to PICU, providing one-day symptom management workshops for children, or facilitating parent support groups.

The 'Clinical' level meets the needs of families experiencing persistent psychological distress requiring longer-term psychological support.

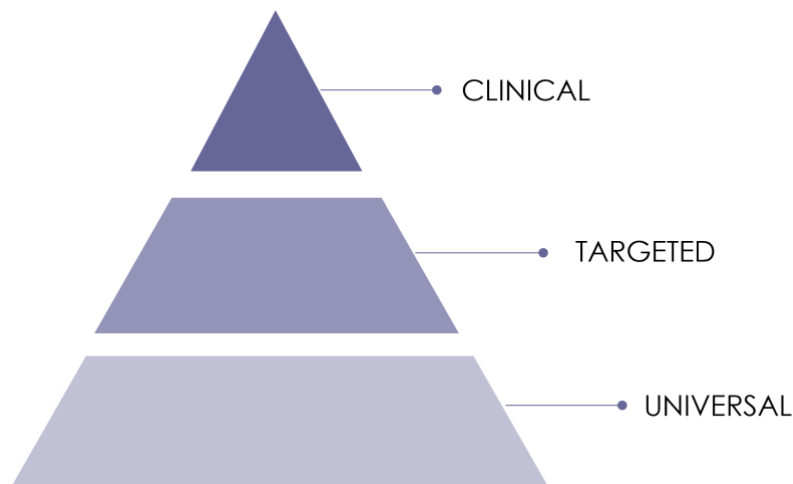


Figure 3. Adapted from 'The Paediatric Psychosocial Preventative Health Model' (Kazak, 2006)

Examples of psychology provision for paediatric respiratory services at these three levels are described below.

4.2.1 Universal support

Psychological screening for children within difficult asthma clinics: Practitioner psychologists should be included as core members of the multi-disciplinary difficult asthma team with the aim of providing psychological support to all children and their families to address issues of adherence, anxiety and depression (Healthy London Partnership, 2017). Depending on time and resources, practitioner psychologists may review children directly within clinic or discuss the psychosocial concerns of children within MDT meetings. NHS England (2016) recommends that 'All patients should undergo a systematic MDT assessment within 12 weeks of referral carried out by a respiratory paediatrician, children's respiratory Nurse Specialist, physiotherapist, and practitioner psychologist ideally (but not exclusively) in a one stop clinic'. Assessment tools such as the Health Anxiety and Depression Scale (HADS), Pediatric Quality of Life (PedsQL), Strengths and Difficulties Questionnaire (SDQ) and Paediatric Asthma Caregivers Quality of Life (PACQL) are useful screening measures for children and their parents/carers, and these can be used as a way of screening for psychosocial difficulty if practitioner psychologists are unable to be present within the clinic itself. Practitioner psychologists also have a role in identifying underlying mental health difficulties and, where difficulties are not specifically associated with physical health needs, referring on to other services such as school counsellors or CAMHS.

Psychological screening for children on LTV: Annual reviews have recently been recommended for all children and young people under the care of LTV teams (NCEPOD, 2020). Where possible, practitioner psychologists should be present at annual reviews, or MDT discussions following annual review. If they are unable to attend, screening measures such as the Pediatric Quality of Life and Family Impact modules of the PedsQL can be used to identify families who may benefit from increased psychological support.

Psychological screening for children with PCD: Since the establishment of specialised psychological provision within PCD services in 2014, it is expected that all children and young people with PCD have an annual psychological well-being review, providing an opportunity for screening of psychological distress, with further direct support being available if needed.

Psychological screening for parent(s)/carer(s): Children look to the adults around them to determine their own emotions and contain their feelings. It is therefore essential that psychological care extends beyond children and young people, to the adults who care for them. Screening for clinically significant levels of depression and anxiety including post-traumatic stress symptoms should be carried out as a routine component of psychological assessment work.

Liaison, signposting & referral to other services: Many children with long-term health conditions have developmental or learning difficulties, either in addition to (e.g. an autistic spectrum disorder) or associated with (e.g. Down's syndrome, Di George Syndrome) their health needs. Whilst paediatric psychology services work with children and young people with developmental or learning difficulties when the difficulties experienced are impacting upon medical treatment and care (e.g. needle phobia, procedural anxiety) or directly related to the physical health condition/diagnosis (e.g. understanding of condition/diagnosis, support with inpatient admissions), they do not typically offer diagnostic assessment and treatment which is typically the remit of local CAMHS and other community services. Practitioner psychologists therefore have a role in liaising, signposting, and referring children, young people and parent(s)/carer(s) to outside services and organisations when further support outside the remit of paediatric psychology services is required.

Psychosocial meetings: Psychosocial meetings can be used by teams to formulate a young person's difficulties, coordinate and evaluate interventions, and manage risk. Practitioner psychologists can help to facilitate discussions regarding the psychological, social and developmental factors which may be influencing a young

person's presentation which the team can then use to address any difficulties more effectively and with a greater understanding (Mercer et al., 2015).

Reflective practice groups: Reflective practice is typically established as a regularly provided space to allow staff to reflect upon the impact of the work they do on their own well-being, to provide an opportunity to think about themes in the team's working and to consider strategies to manage and cope with stress.

4.2.2 Targeted support

A valuable use of a practitioner psychologist's time, particularly when time and resources are scarce, is to screen children and parents at times of increased vulnerability within their paediatric journey, such as during or shortly after an admission to PICU or during their transition to adult services.

Post-PICU follow-up for children with difficult asthma: Children may be admitted to the paediatric intensive care unit because of an acute and severe exacerbation of asthma, with a significant number of children requiring sedation and invasive ventilation during this time. There is a growing body of literature on the longer-term psychological impact for children and young people admitted to paediatric intensive care units (PICU) which consistently demonstrates that a small but significant proportion of children and parents report post-traumatic stress symptoms many months following admission (Colville, Kerry & Pierce, 2008). Initial input for children and parents may involve supporting and facilitating parental coping in the acute setting and in the immediate period following a child's discharge (Colville et al., 2009). More formal trauma-focused interventions, such as narrative exposure therapy or EMDR, may be indicated for a minority of children and/or parents who continue to be very distressed by their experiences following discharge and recovery. Some children may benefit from individualised storybooks to facilitate their understanding of their hospital experiences and help open up conversations between children and parents about what has happened to them (Colville et al., 2021).

Therapeutic groups for children and young people: Children with long-term respiratory conditions, such as difficult asthma, often experience isolation and gaps in their social support because of reduced school attendance. Therapeutic groups provide an opportunity for children to learn and develop more adaptive ways of coping with the challenges that come with living with a chronic health condition as well as providing them with a chance to meet others who share a similar lived experience. One-day group interventions such as Tree of Life groups have a well-

documented evidence base for supporting young people living with long-standing health conditions (Casdagli, Flannery & Christie, 2019), with research demonstrating that these types of approaches enhance self-esteem and contribute to an improved quality of life (Portnoy, Girling & Fredman, 2016).

Specialist joint clinics: Children with long-term respiratory conditions have needs that require the joint expertise of different professional groups. Where there is overlap of assessment and intervention work across disciplines, a strong case can be made for joint-working and the development of multi-disciplinary intervention clinics. This occurs in many areas of paediatrics, for example joint nurse-psychology clinics within paediatric diabetes services. Within paediatric respiratory services one model of this way of joint working is between physiotherapy and psychology to support children and young people with dysfunctional breathing problems. Dysfunctional breathing can have significant impacts on a young person's daily functioning and emotional well-being, with breathlessness and chest pain being commonly reported symptoms. Dysfunctional breathing problems and asthma can occur together, and symptoms of dysfunctional breathing can be mistaken for asthma, leading to overuse of medications and healthcare services. The anxiety experienced by young people in relation to this can further complicate the clinical picture. The introduction of a multi-disciplinary physio/psychology clinic for children with breathing pattern disorders has shown positive preliminary results, with intervention being associated with reductions in physiological and psychological symptoms and improvements in young people's self-reported quality of life (Blundell & Chadwick, 2022).

Psychological support around transitioning to adult health care services: National Institute of clinical excellence guidance (NICE, 2016) highlights the need for psychological support during the transition from paediatric to adult services and identifies the importance of improving psychological and physical health (including adherence and increasing responsibility for health and treatments) during this challenging time. With their understanding of the difficulties that can arise around healthcare transitions, practitioner psychologists are well placed to support young people transitioning to adult services and can help young people to develop greater autonomy and independence in their own healthcare (Gray, Holbrook, Morgan, Saeed, Denson & Hommel, 2015).

Within LTV, transition to adult services can be of particular concern for children with complex and life limiting health conditions and families can experience this period as a time of significant uncertainty (Narayan et al., 2016). The process can be particularly challenging for parents of young people who are cognitively impaired

where there may be concerns regarding the appropriateness of adult services for the child (Patient Experience Network, 2014). Families may have been with their child's paediatric team since birth and so it is also important to recognise that transitioning to adult care may be experienced as a loss of key support networks within the family system. Practitioner psychologists can play a role in helping teams understand the concerns of families and in supporting families through this transition period.

4.2.3 Clinical support

At specific times in a young person's journey, specialist psychological assessment and intervention may be needed. The problems and emotional distress experienced by the child and family can be understood in the context of the young person's experience, medical condition and treatments. Embedding psychological care within medical teams can help to reduce the stigma which often accompanies asking for psychological help.

Difficult asthma: Children and young people with difficult asthma and their parents may require specialist psychological support at any point during their paediatric journey. Specialist intervention should be evidence based and tailored to meet the specific needs of the child, young person and family.

'Ben' is 14 years old. He was recently admitted to PICU with a life-threatening exacerbation of asthma. Worry within the family had increased since this admission and worsened following the Covid-19 pandemic where Ben and his family were advised to shield by his respiratory consultant. His mum was frustrated that Ben was not taking greater responsibility for taking his medications and Ben was angry about the constant nagging from his mum resulting in frequent arguments.

A referral was made to psychology to assess the situation, provide a holistic formulation, and make recommendations about interventions.

A treatment package was designed to facilitate communication between Ben and his parents, support greater family cohesion, clarify parenting strategies and develop Ben's skills in taking medications independently.

In some instances, planned hospital admissions for a detailed review of asthma management may be necessary, the aim of which is to clarify reasons for poor management and agree a plan between the family and team about how to improve asthma control. Assessment and follow-up sessions provided by a practitioner psychologist can be used to explore treatment barriers and adherence issues using motivational interviewing techniques, explore the young person's relationship with their condition and any other psychosocial difficulties which may be impacting on management. Involvement in MDT and safeguarding discussions, and liaison with local services may also be required as part of this intensive intervention.

Long-term ventilation: The initiation of LTV can be a particularly challenging time for families. We therefore recommend that the practitioner psychologist should be involved at the very beginning of a family's LTV journey, and when the concept of LTV is being first introduced, so that families can be supported with the decision-making process and adjustment phase. This could take the form of an assessment with the family and appropriate psychological support offered as required or indirect work through discussions with the team. Practitioner psychologists also have a role in supporting the child and parents during the establishment of LTV, including supporting children who are struggling to tolerate ventilation via a mask or tracheostomy. This work may be particularly beneficial for certain groups of children including younger children, those with intellectual disabilities or neurodegenerative/deteriorating conditions and may involve joint work with a play

'Anna' is 7 years old and has had a tracheostomy since she was a baby. Anna's mother feels let down by services and is struggling to cope with Anna's ongoing and developing needs. She continues to struggle with intrusive memories of Anna's traumatic birth and her long stay in NICU.

Individual psychological work for Anna's mother was arranged by the paediatric psychologist, to provide space for Anna's mother to explore the events surrounding Anna's birth and the traumatic and challenging emotions and responses that understandably arose for her.

Trauma work involved supporting Anna's mother to reduce the intensity of distress associated with hospital admissions.

therapist, where this service is available.

While the transfer home can be a transition that families have been looking forward to, it can also bring unexpected challenges and emotions (Amar-Dolan et al., 2020),

particularly after long admissions. Some families find the transition home a frightening and uncertain time after the support and safety of the ward environment. Parents often describe how their clinical competence (achieved through training with the MDT) is at odds with their low levels of confidence in delivering this care at home. Practitioner psychologists can either work with the MDT to promote the psychological understanding of the transition process or directly with the family where necessary.

4.3 Other roles of the practitioner psychologist

Practitioner psychologists work in a range of ways outside of the clinical work they do with children, young people and families – from working alongside paediatric teams and colleagues, supervising other practitioner psychologists, to working at an operational and strategic level both within and across services.

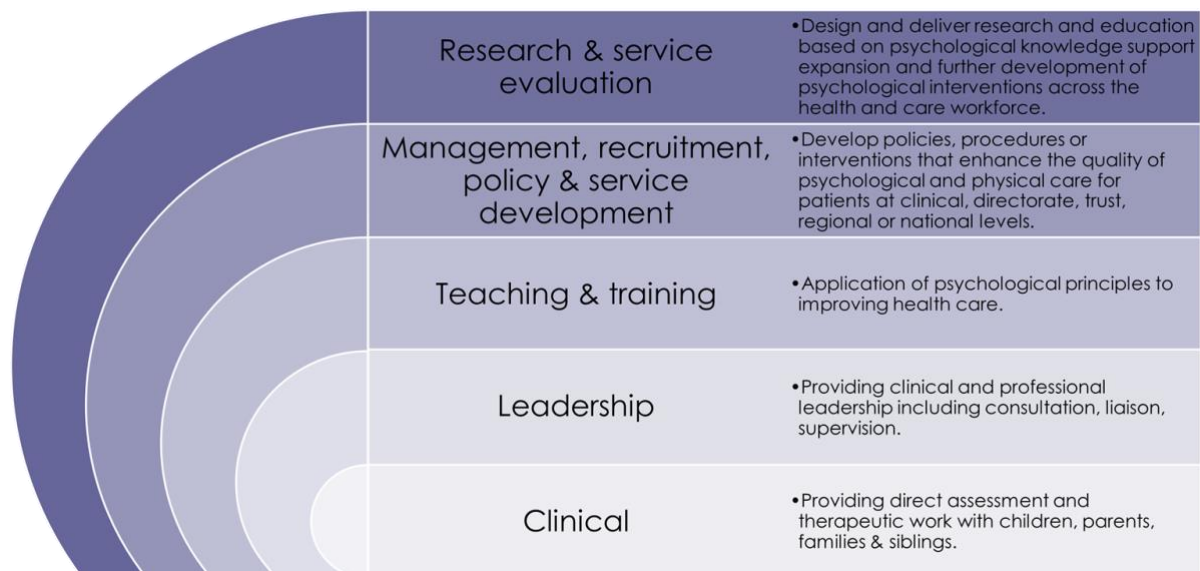


Figure 4. Levels of working

4.3.1 Leadership

The practitioner psychologist is well placed to support the multi-disciplinary team's understanding of a child and the psychological needs of families' without being directly involved in their care. This can happen through discussions within multi-disciplinary team meetings or dedicated psychosocial meetings focusing on the psychological needs of a child and family. Leadership roles also include the role of line management, and clinical and professional supervision to psychology colleagues (including assistant, trainee and qualified clinical practitioner psychologists) as well as offering consultation and supervision to non-psychology colleagues.

4.3.2 Teaching and training

Teaching and sharing knowledge with children, families, hospital staff and other professionals involved in the care of the child is hugely important in promoting a better understanding of psychological needs for different groups of children and their families. This is a way of developing awareness, understanding and skills across professions and services.

4.3.3 Management, recruitment, policy and service development

The practitioner psychologist will be involved in attendance at strategic meetings including clinical governance meetings, business meetings, national service delivery meetings, as well as developing the service alongside respiratory leads and facilitating user and carer involvement in service planning. This may include service development tasks such as designing pathways and processes, implementing the use of standardised outcome measures (including monitoring progress or exploring the impact of respiratory conditions on family members) as well as leading on research projects exploring service users' needs and experiences.

4.3.4 Research and service evaluation

Research is important in clarifying best practice and developing services to improve patient experiences and outcomes, and practitioner psychologists are trained in high level research skills enabling them to complete individual research or contribute to multi-disciplinary research projects within or across services.

5. Service provision and development

Paediatric health services vary enormously in what psychology provision is available. Whilst some paediatric respiratory services within the UK have practitioner psychologists providing dedicated input, other services have no psychology provision at all or have access to general psychology provision which is shared with other paediatric services across an organisation and that can involve reduced access and longer waiting times. This guidance is focused on the recommendation for obtaining dedicated funding for psychology provision to paediatric respiratory patients.

In addition to the human cost, there is a clear economic benefit for accessible and effective psychology services. Psychological input within paediatric populations has been reported to produce beneficial outcomes that range from improved adherence to recommended asthma treatments resulting in improved health outcomes and reduced healthcare use (Graves et al., 2009; Kahana et al., 2008), fewer asthma-related hospital admissions (Smith & Jones, 2015) and improved

emotional and behavioural problems (Kibby, Tyc & Mulhern, 1999). Within adult services, the introduction of a multi-disciplinary case management approach has been shown to significantly reduce hospitalisation in difficult to control asthma patients with prior frequent hospital admission (Burke et al., 2016).

There is currently no explicit national guidance for psychological provision into paediatric respiratory services within the UK. When considering the amount of expert psychological provision for paediatric respiratory services, or for specific areas of work within paediatric respiratory services, e.g., complex asthma, long-term ventilation, primary ciliary dyskinesia services, the complexities and level of psychological need of the paediatric population, as well as the size of the population, should be considered. Direction can also be taken from already well-established standards, for example the Standards of Care for Children and Adults with Cystic Fibrosis (CF Trust, 2011) which recommends 0.5 wte practitioner psychologist per 75 patients.

Following a mapping exercise of psychological provision for paediatric respiratory services across the UK and after reviewing the evidence base, recommendations for staffing ratios for practitioner psychologists working within paediatric respiratory services are provided in Table E1. These recommendations have been developed to facilitate a move towards more equitable service provision across the UK.

The term 'practitioner psychologist' refers to professionals who have undergone certified training and are registered with the Health & Care Professions Council (HCPC) and who have legally protected titles (only those trained and registered appropriately can use those titles to describe themselves and their work). This group includes clinical and counselling psychologists. Both clinical and counselling psychologist professions are accredited at doctoral level (with supervised placements and application of a variety of therapeutic models) to meet standards for accreditation set by the BPS and HCPC.

Table E1. Proposed minimum practitioner psychologist staffing levels (other than CF)

Area of Work	Wte	Clinic size
Long-term ventilation	0.5 (8a)	75
Difficult asthma	0.5 (8a)	100
PCD	0.55 (8a)	150

General respiratory*	0.5 (8a)	150
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**Including children with a neurodisability*

The roles and responsibilities expected of practitioner psychologists are summarised in Appendix 7.3.

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7. Appendix

7.1. Summary of key recommendations from national respiratory guidelines and quality standards relevant to paediatric psychology

Guideline/Quality Standard	Key Recommendations
WC1 Difficult to control asthma assessment in 12 weeks (NHS England, 2016)	<ul style="list-style-type: none"> - 0.2 WTE (1 day) of Band 7/8 clinical Psychologist per centre. - Patients should undergo a systematic MDT assessment within 12 weeks of referral carried out by a Respiratory Paediatrician, Children's Respiratory Nurse Specialist, physiotherapist, and psychologist ideally (but not exclusively) in a one stop clinic.
London Asthma Standards for Children & Young People: Driving consistency in outcomes for children and young people across the capital (Healthy London Partnership, 2020).	<ul style="list-style-type: none"> - Each secondary care facility...should have a referral path for allergy, psychology, and physiotherapy. - Standard 10: There is access to a paediatric severe asthma service with a multi-disciplinary team comprising of a core team: lead respiratory paediatrician with an interest in severe asthma, specialist respiratory children's nurse, specialist respiratory physiotherapist, psychologist.
Children on Long-Term Ventilation Service Specification (NHS England, 2016)	<ul style="list-style-type: none"> - A multi-disciplinary team approach must include input from paediatric psychology.
Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK (2011)	<ul style="list-style-type: none"> - 0.5 wte clinical psychologist per 75 patients.
ECFS Best Practice Guidelines: the 2018 revision	<ul style="list-style-type: none"> - The CF team needs to screen annually for mental health symptoms in people with CF (≥ 12 yrs) and parents of children and young people with CF. - A CF team psychologist should also assess annually for other significant or emerging emotional health difficulties and for health management problems. - Specialist mental health professionals in CF teams (e.g., clinical psychologists, psychiatrists) can provide a range of well-established therapies and strategies through the diagnosis and formulation of complex emotional health or health management issues.
NHS Standard Contract for Paediatric Medicine – Service Specification (NHS England, 2014).	<ul style="list-style-type: none"> - A specialist team would consist as a minimum of: Consultant trained in paediatric respiratory medicine...clinical psychologist, speech & language therapist, occupational therapist, and social worker.

7.2 Summary of key recommendations from national respiratory guidelines and quality standards relevant to paediatric psychology

Guideline/Quality Standard	Key Recommendations
Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care 3 rd Edition (2019)	<ul style="list-style-type: none"> - 1.0 wte practitioner psychologist per 300 patients.
Paediatric Congenital Heart Disease Standards: Level 1 – Specialist Children’s Surgical Centres, NHS England (2016)	<ul style="list-style-type: none"> - Minimum of 0.25 wte psychologist per 100 children undergoing cardiac surgery each year. - In addition, 1.0 wte psychologist must be employed for each network.
Diabetes in children and young people: Quality Standard (NICE, 2016)	<ul style="list-style-type: none"> - Multidisciplinary paediatric diabetes teams should include a psychologist and provide access to them in an appropriate timeframe.
Quality standards for paediatric gastroenterology, hepatology and nutrition (RCPCH, 2017)	<ul style="list-style-type: none"> - The IBD service must have defined access to the clinical network and include the following with an interest in IBD: children’s nursing expertise; paediatric dietetics; mental health support professionals; clinical psychologists and counsellors; rheumatologist; ophthalmologist; dermatologist; radiologists; endocrinologist; adult gastrointestinal physician interested in adolescent IBD; gastrointestinal pharmacist; and a nutrition support team.

7.3 Summary of roles and responsibilities of practitioner psychologists

Level of work	Roles and responsibilities
Clinical	<ul style="list-style-type: none"> - Specialist psychological assessment and intervention for children, young people and families referred both as inpatients and outpatients. - Attendance at ward round, MDT meetings, psychosocial meetings. - Complex liaison including attendance at safeguarding case conferences (where necessary), liaising with other mental health professionals involved in patient care outside of the hospital setting, liaison with educational organisations and community services - Screening & signposting to other psychological and mental health services including CAMHS, school counselling services.
pec	<ul style="list-style-type: none"> - To receive clinical professional supervision from a senior clinical psychologist. - Participation in CPD & wider department activities. - To provide psychosocial advice and consultation for the paediatric respiratory team including discussing psychological needs of patients who may not be referred to the psychology service but are being cared for by the paediatric respiratory team. - To provide professional and clinical supervision of other psychologists, other psychosocial workers, clinical psychology trainees.
Teaching and training	<ul style="list-style-type: none"> - To provide professional post-graduate teaching and training to other MDT staff's psychological work as appropriate. - To contribute to the pre- and post-qualification teaching of psychologists as appropriate. - To provide training on psychological issues to staff working with the patient group across a range of agencies and settings, where appropriate (including the paediatric respiratory team, other paediatric teams, educational organisations).

<p>Management, recruitment, policy and service development</p>	<ul style="list-style-type: none"> - To contribute to local and national policy and procedure development (e.g., NIV initiation, post-PICU screening, annual review screening within difficult to control asthma). - Representation and strategic working on national committees such as Paediatric Psychology Network Committee, Psychologists in Paediatric Respiratory SIG, BPS, ACP-UK. - Contribution to national guidance and policy (e.g. peer reviewer on NCEPOD).
<p>Research and service evaluation</p>	<ul style="list-style-type: none"> - To undertake project management, including complex audit and service evaluation within the paediatric respiratory service to help develop service provision. - To contribute to research (including involving patients in their medical treatment, quality of life, ethics of LTV, multi-centre outcome studies, supervision of psychology doctoral theses). - To attend and contribute to conferences, presentations & teaching (e.g. BTS, Kings Paediatric Respiratory Conference).