Young People's Health Partnership

# Children, young people and families' experiences of chronic asthma management and care

## Evidence from existing research

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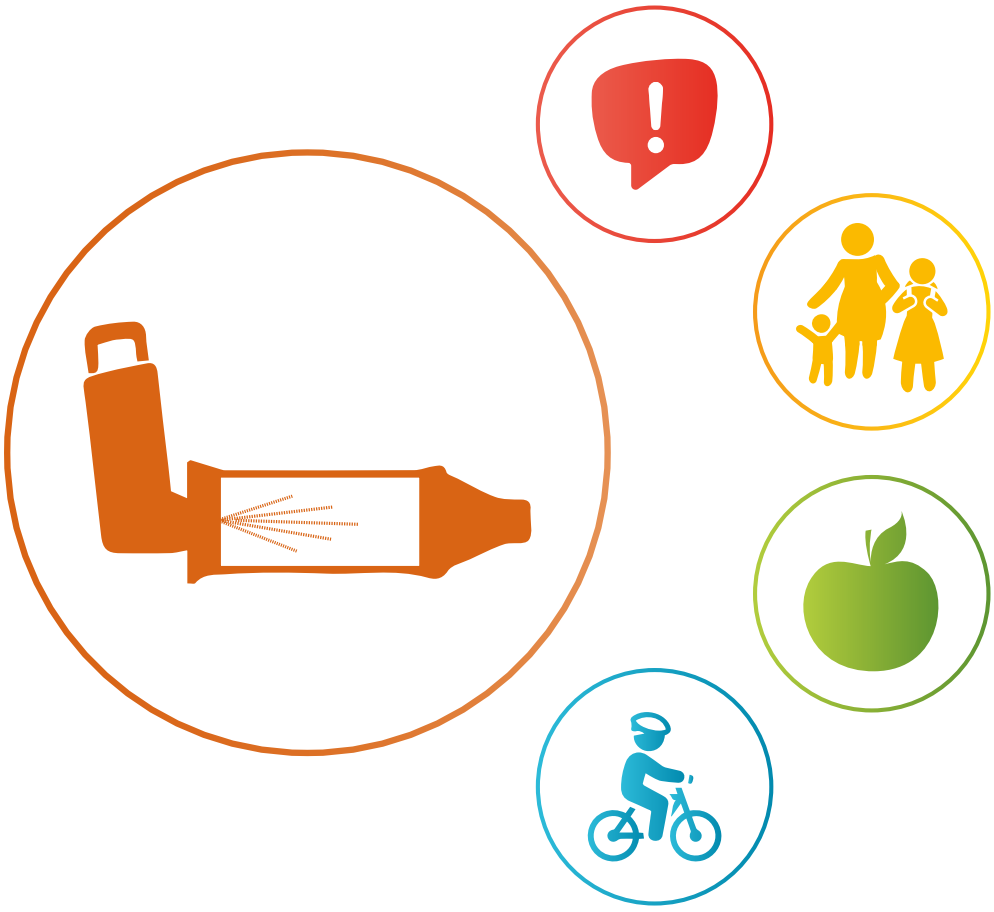

# Children, young people and families' experiences of chronic asthma management and care

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January 2021, James Kenrick and Emma Rigby, Association for Young People's Health

### 1. Executive summary

In this scoping review we sought to understand children, young people and families' experiences of managing and receiving care for chronic asthma. The review considered the impact of inequality and a range of social factors on effective asthma management; the specific experience of marginalised groups; and how children, young people and families think care and management could be improved.

The results suggested:

- Children and young people's most positive experiences of NHS care are when they obtain easy and quick access to specialist doctors and nurses who understand them, can communicate in terms they understand and can provide coordinated, age-appropriate care.
- Children and young people want more information, advice and support so they can better manage their condition themselves.
- Variations in care are preventing those children and young people who are most in need of services from receiving the high quality care they need, whilst a range of social factors can act as barriers to effective self-management.
- Child- and young person-centred treatment pathways, models of care and self-management approaches should be co-developed with young people and families based on a thorough understanding of their preferences, thinking and behaviour.
- The views of children, young people, parents/carers and clinicians often differ. There has been little participatory research which has focussed specifically on eliciting the views and experiences of children and young people (up to age 25) in isolation from their parents and clinicians.
- There are significant gaps in the evidence. There is a particular need for more research to understand the views and experiences of older adolescents and young adults, and young people from marginalised groups including the experiences of minority ethnic groups.

# 2. Introduction

## 2.1 Purpose of this review

Asthma is the most common long term medical condition experienced by children and young people in the United Kingdom (UK)[1]. Yet it remains poorly diagnosed and, too often, poorly controlled, leading to avoidable emergency treatment and deaths.

There is an increasing recognition amongst academics,[2] health professionals[3] and policy-makers[4] that understanding the experiences and views of children, young people and families is likely to be an effective route to improving asthma care and outcomes.

The Young People's Health Partnership is working with the NHS England and NHS Improvement Children and Young People's Transformation Team, Royal College of Paediatrics and Child Health, Association for Young People's Health, Race Equality Foundation and Friends, Families and Travellers to better understand:

- what children, young people and families affected by chronic asthma experience in relation to their care and how they would like it to be improved;
- the experiences of marginalised groups of children, young people and families in relation to asthma management;
- how marginalised groups of children, young people and families feel communication and implementation of better care could be best achieved.

This report sets out the main findings from the first stage of this work, a scoping review of evidence from existing research.

## 2.2 Scope

The review focussed on recent evidence from the UK of children's, young people's and families' experience of managing and receiving care for chronic asthma.

The primary emphasis was on the experiences of children and young people aged 0-25 years. However, the review also sought to understand the experiences of their parents, carers and wider families. Where possible, we have attempted to identify the specific experience of marginalised groups and to consider the impact of inequality.

Whilst the review was specifically concerned with 'chronic asthma' (see Box 1 for definition), we found that the literature rarely distinguished between types of asthma and used a range of terminology. We took an inclusive approach including all studies as long as they did not explicitly exclude chronic asthma.

The review examined evidence relating to all settings in which NHS asthma 'care' is delivered and adopted a broad interpretation of 'management', covering the important interface between the formal health and care system and how children, young people and families manage their own condition at home, at school and in the community. This reflects the reality that patients with chronic diseases must manage their own health and care on a day-to-day basis. Understanding how patients self-manage chronic asthma, and the social and environmental factors that impact on effective self-management, is particularly important in relation to adolescents and young adults who are moving away from dependence on parents and carers, becoming independent users of healthcare and in some cases transferring out of paediatric care.

**Definitions**

**Children and young people**

In this paper, we use the term 'young people' to refer to those aged 10-25, in line with The World Health Organisation's definition,[5] and the term 'children' when referring to those under the age of ten. The term 'young adult' is used when specifically referring to those aged 18-25.

**'Asthma' and 'chronic asthma'**

The most widely accepted definition of asthma is*: 'a heterogeneous disease, usually characterised by chronic airway inflammation. It is defined by the history of respiratory symptoms such as wheeze, shortness of breath, chest tightness and cough that vary over time and in intensity, together with variable expiratory airflow limitation. Airflow limitation may later become persistent.'* (Global Initiative for Asthma, 2020)[6]

There is agreement in various definitions that asthma is typically a chronic, long-term condition.

For this paper the team delivering the project developed the following youth-friendly working definition of 'chronic asthma' which was agreed by the NHS CYP Transformation Team:

*'Chronic asthma means that you need to use your preventer inhaler (normally purple, brown or orange) every day and that over the last year you may have had some times when you needed to use your reliever inhaler (normally blue or white) or go to the doctor to control your breathing / asthma.'*

**Children and young people's descriptions of asthma symptoms**

*'I cough and I get wheezy….It hurts'* (6 year-old)
*'I start to get breathless and I can't breathe as well as I always do'* (6 year-old)
(Source: Searle et al. 2017)

*'I can't let the breath out'* (13 year-old)
*'kinda struggling for air'* (14 year-old)
*'I don't have it all the time, just every now and then… sometimes, like.'* (13 year-old)
*'you'd feel it in your chest… a bit of a cough or a scratch coming on here [points to base of throat] so you'd take a quick drag of it [inhaler] and then you'd be off again, right as rain.'* (16 year-old)
(Source: Monaghan and Gabe 2015)

### 2.3 Methods

Most published literature about asthma in children and young people focuses on biomedical rather than social factors and there is a lack of recent, published participatory research in this field. Thus, a broadly inclusive approach was taken to the review, encompassing all types of studies and grey literature including policy reports. The focus was on papers from the UK.

Relevant papers were identified through a call for evidence, online searches, a review of relevant aspects of existing data compendiums, and consultations with colleagues working in the field. We are grateful to RCPCH &Us, the Royal College of Paediatrics and Child Health's children and young people's voice programme, who have shared unpublished data from an extensive programme of engagement work conducted with children, young people and parents/carers that has supported paediatric asthma programmes.[7]

The findings from this review will inform a programme of engagement work, including online workshops and one to one interviews, focused specifically on filling gaps in the evidence-base. A final Engagement Report from this review and engagement work has been produced alongside this Scoping Review.

## 3. Findings

This section of the report sets out the main findings from our scoping review.

We start by providing some contextual information on **the prevalence and outcomes of asthma in children and young people**, including emerging evidence on the impact of the Covid-19 pandemic.

This is followed by findings on children's, young people's and families' **experiences of asthma care in formal healthcare settings**, including GP surgeries, emergency departments and specialist asthma clinics.

We then explore some of the **social aspects of asthma management and care**, including experiences at school and the impact of factors such as stigma, exclusion, knowledge, awareness, perceptions and attitudes on how children and young people view and self-manage their condition.

Finally, we explore **the role that inequality plays** in determining the quality of children and young people's asthma care and review the limited available evidence on the specific experiences of marginalised groups.

Throughout the report, we identify gaps in the evidence base, together with suggestions from the literature – and, particularly, from children, young people and families themselves – for how asthma management and care could be improved.

### 3.1 Context: the prevalence and outcomes of asthma in children and young people

Around 1.1 million children (one in eleven) currently receive asthma treatment in the UK, making it the most common long term medical condition among this age group.[8] It is also the most common reason for urgent admissions to hospital in children and young people in England.[9]

The UK performs poorly compared with other European countries in children and young people's outcomes of asthma management. An analysis of data from 19 countries found that the UK had the highest asthma mortality rate among young people aged 10-25 in 2016 out of the 14 European countries included in the comparison.[10] Previous declines in mortality rates amongst young people in the UK have stalled over the last decade,[11] and deaths from asthma across all age groups increased by 33% in England and Wales between 2008 and 2018.[12]

Emergency admissions and deaths related to asthma are largely preventable with improved management and early intervention. The National Review of Asthma Deaths (2014) found that there were preventable factors in 90% of childhood deaths, whilst 46% of the children who died had received an inadequate standard of asthma care. Many had inadequate asthma management plans in place or failed to seek or receive medical care early enough when acutely ill.[13] Furthermore, emergency admissions for asthma are strongly associated with deprivation.[14]

Asthma which is not under adequate control can impose a significant psychological burden on children and young people, which, in turn, can exacerbate asthma symptoms.[15] Moreover, both poor asthma outcomes and poor mental health outcomes disproportionately affect adolescents from poorer backgrounds.[16]

Asthma also has significant social implications for children, young people and their families, including absences from school and work, restricted activity, and stress.[17] Further, whilst asthma often begins in childhood,[18] it can lead to cumulative lung damage[19] and psychological ill-health in adulthood.[20]

These adverse consequences are avoidable through effective management and control of symptoms. However, improvements in levels of basic asthma care have stalled,[21] with the management of childhood asthma found to be *'often sub-optimal'*.[22] Only 26% of children aged 0-15 with asthma are deemed to have 'controlled asthma'.[23] We should note here that new data from the National Asthma and COPD Audit Programme is due in Spring 2021 and will be helpful in adding to our understanding of the current state of asthma care.

***The impact of the Covid-19 pandemic***

Whilst the full impact of the pandemic on children and young people's asthma care remains unclear at the time of writing, a limited amount of evidence has emerged in recent months.

Early evidence does not suggest that children and young people with asthma are more susceptible to Covid-19 infection than others of their age, although they may be more likely to require an intensive care admission if they contract Covid-19.[24]

Presentations at emergency departments from children and young people with asthma symptoms fell during the initial lockdown.[25] The reasons for this remain unclear, with suggested explanations including a reduction in other respiratory viruses; improved protection from pollution, viruses and allergens from mask wearing; improved treatment compliance due to spending more time with caregivers; a reduction in outdoor pollution as well as fear of contracting Covid-19 when in hospital.

Conversely, there are several factors at play that could increase the risk of poor asthma control. There has been an understandable reluctance on the part of many families to attend hospital and GP services during the pandemic, whilst the switch to more remote delivery and telemedicine has created additional challenges for the assessment of asthma symptoms and access to healthcare. Some young people from marginalised groups have reported particular challenges accessing remote healthcare services during lockdown due to being digitally excluded, highlighting the impact of the pandemic in widening health inequalities.[26] Those living in poor housing may also experience greater exposure to indoor allergens, second-hand smoke and mould.

Nadia et al (2020) explored the psychological and emotional impact of the pandemic on children and young people aged 4-18 under the care of an asthma clinic serving South London and South East England. Many children and young people reported increased levels of irritability, anxiety, and difficulties with concentration and sleeping, although only a minority felt that concerns regarding Covid-19 had influenced their asthma symptoms. Most parents were worried about access to healthcare services if their child had an asthma attack during the pandemic.[27]

## 3.2 Experiences of NHS asthma care

### *Experiences of asthma care in GP surgeries*

With most asthma care provided in primary care,[28] understanding children and young people's experiences of asthma care in GP surgeries is critical. The key role of GPs includes: early identification; accurate diagnosis; prescribing appropriate medication and devices; provision of an asthma care plan (e.g. a Personalised Asthma Action Plan); undertaking regular asthma reviews; making timely referrals to specialists; and providing information and advice to enable the patient to self-manage their condition.

Health service data indicate that asthma in children and young people remains poorly diagnosed[29] and that many people with asthma are not on GP registers.[30] NHS England state that less than 25% of children with asthma have a Personalised Asthma Action Plan.[31] The National Review of Asthma Deaths (2014) found evidence of excessive prescribing of reliever medication and under-prescribing of preventer medication, and that there was no evidence that an asthma review had taken place in general practice in the last year before death for 43% of people (of all ages) who died.[32] Asthma UK have reported that the most common reason given by young adults for not attending a review was that they did not receive a reminder that their review was due.[33] This situation is compounded for families from the most excluded groups with no fixed address or ID where registration to primary healthcare is refused.

RCPCH &Us Voice Bank (2018-2020) provides rich qualitative data regarding the experiences of children, young people (aged 0-25 years from a variety of ethnic backgrounds) and their parents/carers when accessing asthma care in GP surgeries, including their views on how care could be improved.[34] Children and young people said they wanted:

- Specialist GPs or asthma nurses who know a lot about childhood asthma. Many children and young people reported poor experiences with GPs who lacked expertise in childhood asthma. They tended to have more confidence in specialist asthma nurses.
- A care plan that is written down and ensures consistency with medication dosage, so that young people have more control over their illness and their plan.
- Quicker referrals to specialist asthma clinics and consultants.

- Accessible appointments. They wanted to be seen quickly and to have more time with their GP so they could build a relationship.
- Better communication. They wanted to understand what was being said to them and to be given a choice of options, but sometimes felt GPs talked rather than listened to them. They also mentioned letters getting lost and a lack of communication between the GP and the hospital.
- Greater consistency in doctors and in diagnosis.
- Information and education, so they can understand how to look after themselves.

Parents and carers participating in RCPCH &Us Voice Bank (2018-2020) engagement work echoed many of their children's concerns and priorities, but, reflecting their different perspectives and expectations, also highlighted difficulties and delays in obtaining a formal diagnosis. Experiences included being told they could not get a diagnosis of asthma before the age of 5;[35] getting different diagnoses from different doctors; and having to push for a referral to a specialist. (See Box 3 for quotes from parents and carers.)

Separate engagement work carried out by Healthwatch Blackburn with Darwen (2019) with 85 young people aged 0-18 and their parents/carers found that young people with complex needs wanted their GPs to provide them with a visual of how to manage their inhaler that they could keep referring to at home; and that parents also wanted more information for themselves.[36]

**Parents' and carers' views on GP care**

*'One doctor [in] our practice has a clue about asthma in children. The rest have limited knowledge about asthma. All GPs should have an asthma children's nurse practitioner. It's a really scary thing and they need to know about it.'*

*'Awareness needs to improve – the health service needs to understand more about asthma, they just give you an inhaler for everything and we didn't know what we were taking it for.'*

*'We have been sent away on several occasions saying chest is clear and that evening ended up in [hospital] following an attack.'*

*'If our GP is away – I found it a nightmare for anyone to listen to me – even the head of the practice! I need it written down by the doctor how they usually present when in an attack so this can be passed on from person to person otherwise they look at me as if I have two heads.'*

*'Support isn't good, prescriptions still take 3 days even if emergency, this should not be the case with inhalers.'*

Source: RCPCH &Us Voice Bank (2018-20)

### *Experiences of emergency asthma care*

Effective routine care in GP surgeries and self-management is sufficient in many cases to control children and young people's asthma. An acute asthma exacerbation requiring emergency hospital admission is a serious outcome and requires urgent care informed by a clear care / asthma action plan. Whilst emergency hospital admissions for asthma are falling,[37] there is evidence of variation in the quality of emergency care. An audit of asthma care in adults and children by the Royal College of Emergency Medicine (2017) found that only a minority of patients received vital assessments or potentially life-saving treatments in an acceptable timeframe, whilst discharge advice and follow-up was often inadequate.[38] This is concerning, as The National Review of Asthma Deaths found that 10% of asthma deaths (across all age groups) occurred within four weeks of hospital discharge following treatment for an acute attack.[39]

The most in-depth source of qualitative data on the experiences of children, young people and parents/carers when they had accessed emergency care is RCPCH &Us Voice Bank's (2018-2020) engagement work in asthma clinics.[40] Some children and young people described their experiences as 'scary' or 'frightening', but most had very positive views of the quality of care they received, reporting 'quick', 'friendly' and 'excellent' service. They identified three clear priorities for emergency treatment:

- They want to receive medication immediately on arrival, with their care plan made available to staff so that they get the right dosage.
- They want to see an asthma specialist on a ward immediately.
- They want to know what's going on, who is helping them and how the treatment is helping.

Parents and carers interviewed by RCPCH &Us Voice Bank (2018-2020) and Healthwatch Blackburn with Darwen (2019) generally shared their children's positive experiences, but referred to some problems on visits to A&E. These included long waits for ambulances; the absence of an asthma specialist on arrival; poor communication between GPs, hospitals and specialists;[41] and lack of follow up to ensure correct medication.[42]

### *Experiences of care at specialist asthma services*

NICE guidelines state that patients with severe or uncontrolled asthma must be referred to a specialist asthma service where they can benefit from the full range of asthma tests and be assessed for specialist treatments tailored to their specific type of asthma.[43] Some specialist asthma services operate within specialist children's hospitals, but only a very small percentage of people with asthma currently access ongoing care at a specialist asthma centre.[44]

The main source of evidence on the experiences of those children and young people who do manage to access specialist asthma services again comes from RCPCH &Us Voice Bank (2018-2020). Children and young people interviewed in tertiary services (specialist children's hospital clinics) reported extremely positive views of the service, which contrasted with their less positive experiences of care received in primary care and in District General Hospitals. They described receiving excellent care from staff who were 'more switched on', listened to them, built a relationship with them, understood the care they needed and gave them the right information. They described getting everything they needed through a holistic approach, which included undergoing tests; getting their plan sorted; receiving regular check-up calls; and being given important information leaflets. As a result, children and young people felt happier. The main drawback cited was the distance from home of the clinic location, sometimes requiring inconvenient travel and time away from school or work. Children and young people's top priorities included reiterating the importance of a care plan to support consistency with medication and save delay at GPs and A&E; seeing the same consultant; and having more local clinics or mobile clinics.[45]

### 3.3 Social aspects of management and care

The extent of children and young people's need for and use of NHS care is determined, to a large extent, by how effectively their chronic condition is managed and controlled on a day-to-day basis at home, at school and in the community. This section considers relevant social aspects of asthma management and care, including children and young people's experiences at school and the impact of factors such as stigma, exclusion, knowledge, awareness, perceptions and attitudes on how they view and self-manage their condition.

#### *Experiences of asthma care and management at school*

A number of studies identify schools as an important setting for the delivery of NHS asthma care. For example, a randomised controlled trial found that asthma clinics held in secondary schools increased clinic attendance and uptake of asthma reviews amongst adolescents.[46] Szefler et al's (2020) worldwide charter for children with asthma identifies school nurses as having a key role in identifying undiagnosed asthma, making referrals to GPs and asthma specialists and providing ongoing support to pupils.[47] More broadly, schools have a legal duty under the 2010 Children, Schools and Families Act and the Children and Families Act 2014 to look after children with medical conditions, including asthma. Providing appropriate asthma care and support at school is necessary for children and young people's safety, wellbeing and academic performance. Whilst some older children and young people may be fully independent with their condition, younger children, children and young people with learning difficulties or those newly diagnosed are likely to need support and assistance from school staff during the school day, to help them to manage their asthma.

Data from RCPCH &Us Voice Bank (2018-2020) indicate that whilst some children, young people and parents/carers praised schools as being very understanding and supportive,

others reported that a lack of understanding of asthma amongst school staff left children and young people feeling unsafe and unable to access medication when they needed it.[48] Engagement work conducted by Healthwatch Blackburn with Darwen (2019) found that only a minority of children and young people had easy access to their medication at school, whilst the majority of parents/carers were unaware who was the lead person within the school regarding their child's asthma.[49] Similarly, Jago at al (2017) found that both children and parents reported limited access to their inhaler at school and described having to go to the school office to receive medication. Many parents cited school policies, which stated inhalers should be kept in the school office rather than with the child, as a barrier to the child engaging in physical activity.[50]

Children and young people reported to RCPCH &Us Voice Bank (2018-2020) that they needed more help at school to feel safe and supported with their asthma care. In particular, they wanted: [51]

- school staff and their peers to understand the seriousness of the condition and its impact on their health and energy levels;
- staff to acknowledge that they are self-managing their condition and support them to do so;
- to be supported to participate in school trips and physical education;
- a dedicated person at the school to support them;[52]
- a care plan to be in place at school, with the hospital in touch with the school about it.

*'I have three children, two of which have asthma. During the winter months they struggle with their breathing more so than during the rest of the year. They have both been off school a considerable amount of time when they are unwell. Both on different occasions have been admitted to the hospital several times with 2-3 day stays due to their asthma not being in control. I had shared their personalised action plans with the school with one of the key points on the plan was to ring an ambulance if they are wheezing or struggling to breathe before they try to get in touch with me. Instead they continuously tried to contact me (I was at work) before they did anything about it. By the time I got to the school and took him to the hospital, a health professional at the hospital had told me if it took any longer to get treatment the outcome could have been very different.'*
Parent (Source: Healthwatch Blackburn with Darwen, 2019)

*'I struggle with my breathing when I am exercising. PE lessons give me anxiety as I am worried if I start breathing loudly or wheezing. It's embarrassing for me to tell the teacher in front of the whole class.'*

14 year-old (Source: Blackburn with Darwen Healthwatch, 2019)

***Self-management***

Asthma in children and young people can usually be well managed using preventative medication[53]. However, research by Harris et al (2017) with young people in London secondary schools found that almost half had poor control of their symptoms, most often due to a lack of understanding of the condition, over-estimation of control and/or poor adherence to medication.[54] The National Review of Asthma Deaths (2014) emphasised the vital importance of improving patients' self-management in order to improve outcomes,[55] and several studies have concluded that better ways must be found to educate and empower young people with asthma to take control of their condition.[56]

Key elements of self-management of chronic asthma have been identified as:

- understanding one's condition and personal triggers;
- knowing what to do to stay well;
- knowing how, why and when to take asthma medications correctly;
- recognising when asthma is not controlled and what to do when experiencing symptoms;
- knowing when and how to seek emergency advice;[57]
- having a positive attitude[58] and the confidence to deal with both the medical and emotional management of the condition.[59]

Age-appropriate approaches that foster adolescents' self-efficacy are widely considered to be most likely to succeed.[60] The evidence shows that high quality educational interventions can result in an improvement in adherence to therapy and in most asthma outcomes.[61] This may include short, simple, well-designed programmes providing key information on asthma management, an easy to understand co-produced action plan, and inhaler technique training;[62] and peer-to-peer schemes within schools that complement the role of school nurses.[63]

Designing effective approaches aimed at improving self-management requires a comprehensive understanding of young people's current capabilities and the wider social influences that impinge on self-management.

***Knowledge, awareness, perceptions, attitudes and assessment of capabilities***

The literature frequently refers to young people and their parents perceiving themselves as more capable and effective in managing their asthma than health professionals believe them to be.[64] Whilst some earlier studies come across as somewhat judgemental on this topic, increasingly, there is a recognition of the need to better understand the views, experiences and attitudes and beliefs of children, young people and families.

Several studies have remarked that children and young people tend to normalise asthma by minimising the significance of the condition. A study by Monaghan and Gabe (2015), based

on interviews with children and young people aged between 5 and 17 in south-west Ireland, including young people from the Irish Traveller community, found that young people overwhelmingly defined their asthma as an unremarkable condition, even when their parents described it as 'really bad'. Whilst younger children sometimes conveyed a sense of pride in their ability to manage their condition, older young people were more likely to dismiss their asthma as boring.[65]

Searle et al (2017) identified an apparent non-alignment between young people's and parents' tendency to normalise the condition, and to manage asthma as an intermittent acute illness rather than one that requires preventative medication, and professionals' adoption of a 'biomedical' model in which asthma is seen as an acute and chronic disease.[66] Such perceptions amongst young people and parents are highly significant, as they can directly lead to underestimation of the severity of the condition, overestimation of asthma control and poor adherence to treatment.[67]

Interestingly, the evidence from qualitative studies indicates relatively high levels of responsibility and willingness to take medication amongst younger children,[68] but this has been noted to reduce during adolescence when adherence to treatment may be perceived as embarrassing, a chore or conflicting with other activities.[69] Teenagers are also less likely to attend appointments.[70] Boys may be more willing to tolerate asthmatic symptoms than girls, but less willing to take prescribed medications, particularly in public settings.[71] This points to the need for different approaches to care and management for young people in response to their life stage and developmental needs.

**'Would you like to get tips and advice to help keep your asthma under control?'**

*'It would be helpful to know the different types of asthma you can get and if you control them all the same. Would also be good to know some breathing techniques to help strengthen your lungs.'*

*'Especially how to deal with asthma whilst in school and doing sports'*

*'I would like some information on how to keep it under control'*

*'It would be helpful to know if you're having severe, moderate or mild asthmatic needs and how to treat those needs in a clear detailed plan'*

*'How to help control/prevent my asthma before exercise and during the winter when I can sometimes struggle in the cold weather.'*

Young people (Source: RCPCH &Us Voice Bank, 2018-2020)

***Stigma, identity and exclusion***

Research has identified a number of social impacts of asthma on children and young people that also act as barriers to the successful management of the condition, including social stigma; embarrassment; restricted social lives; and frustration that others do not understand their condition.

Jago et al (2017) found there was significant social stigma attached to using inhalers at school. Younger children (aged 6-7 years) reported being reluctant to ask for their inhaler in front of peers because they were worried about standing out and feeling different.[72] Similarly, Harris et al (2017) surveyed 689 London schoolchildren aged 11 to 18, 42% of whom reported feeling uncomfortable using their inhalers at school.[73]

In an earlier qualitative study using conversational style interviews with 25 young people aged nine to 16 years and their parents/carers in Manchester by Callery et al (2003), young people emphasised the extent to which they appeared different to their peers.[74] Similarly, in-depth interviews with 55 young people aged 11-16 living in West London found that asthma restricted their lives at school and recreationally and that social relations help to determine the extent to which asthma episodes can be managed.**[75]** It is important to view this evidence in relation to children and young people's developmental life stage and the unique pressures they face.

Asthma UK (2009) reported that children and young people were often unable to fully take part in school life because of school absences, a lack of understanding and support from teachers and '*being singled out as being different to their classmates.'*[76] Searle et al (2017) found that children did not like to miss school as it disrupted their learning and affected them socially, sometimes leading to disengagement from others.[77] Similarly, children and young people participating in RCPCH &Us Voice Bank's (2018-2020) engagement said that missing school left them feeling excluded and alone and made it hard for them to make friends.[78] Meanwhile, De Simoni et al (2017) found that young people and young adults often talked about feelings of embarrassment about their asthma diagnosis and taking inhaler treatment in public, which could lead to derision and exclusion from social activities.[79]

Social impacts such as these, in turn, can affect children and young people's self-image and social identity. For example, a mother of an 11 year-old interviewed by a youth worker for RCPCH &Us Voice Bank (2018-2020) in an asthma outpatient clinic said: *'He sees himself as a sickly child'*.[80] Similarly, a child interviewed by Swansea University (2020, unpublished) in ongoing research described their asthma diagnosis as *'a life sentence of not being able to breathe properly'*.[81] Iley (2010), in reviewing the evidence on the impact of asthma on the everyday lives of children, found there were gender differences in how children view their own health and deal with illness, citing evidence that girls were more likely to incorporate their chronic illness into their social identities and to curtail aspects of their lives such as

sport. Boys, by contrast, were less likely to accept that their asthma was part of their male identity and were more likely to minimise the impact of the illness, seeing it as a stigmatising condition.[82] The RCPCH State of Child Health (2020) also highlights the importance of mental health input to support asthma care[83].

## 3.4 The impact of inequality

### *Variations in asthma incidence and care*

Social and economic differences have been found to be a major cause of health inequalities amongst young people.[84] There is evidence that asthma is more prevalent in more deprived communities,[85] with incidence higher in the north than the south.[86] In one study, whilst area deprivation was strongly associated with diagnosed asthma in boys, this was not found to be the case in girls.[87] However, emergency hospital admissions for children and young people with asthma demonstrate a clear relationship with socio-economic factors,[88] with those from the most deprived areas of the UK being almost twice as likely to be admitted as those from the least deprived areas.[89]

Young people in deprived areas are also more likely to be exposed to environmental factors that can act as asthma triggers. For example, they are more likely to smoke,[90] be exposed to higher levels of second-hand smoke and environmental pollution,[91] live in poor quality housing (with exposure to mould), have poor diets and be obese.[92] For example, poor air quality is an issue which particularly affects Gypsy and Traveller communities due the location of sites next to motorways and in areas with poor air quality [93]. Further, Asthma UK (2020) have reported significant variation in the quality of basic asthma care received depending on socio-economic group, with lower income groups less likely to be asked about their symptoms, to have their inhaler usage assessed or to have their adherence to their preventer inhaler discussed at their asthma reviews.[94]

Young adults are the age group most likely to be diagnosed with asthma,[95] but are the least well-served by asthma services. Asthma UK's analysis of their Annual Asthma Survey focussed in 2018 on responses from young adults aged 18-29 years. They found that two thirds of this age group were not receiving basic asthma care; 88% had uncontrolled asthma; they were more likely than other age groups to have had an asthma attack in the last 12 months and to be admitted to hospital due to their asthma; and they had poor levels of adherence to medication.[96]

There are also notable differences by ethnic group. There are significantly higher rates of asthma incidence in black and minority ethnic (BAME) groups in England and Wales, with high rates reported among second and third generation descendants of South Asian and African Caribbean migrants[97] and Irish children living in England.[98]

Given these stark inequalities, it is vital to understand the experiences of these marginalised sub-groups if care is to be improved and targeted.

***Differential experiences of asthma care and management amongst marginalised groups***

As part of our review, we searched for studies exploring the specific experiences of groups that are marginalised (including, for example, young adults, young people from BAME communities and young carers), but found a dearth of recent research from the UK.

The notable exception is the comprehensive Management and Interventions for Asthma (MIA) study (Lakhanpaul et al, 2014-20), which has explored the experiences of British South Asian families. As part of a wider study to identify barriers to optimal asthma management and to inform culturally appropriate interventions to improve management, semi-structured interviews were conducted with children aged 5-12 years,[99] parents, carers and family members[100] from both South Asian and, for comparison, White British backgrounds. Interviews revealed considerable similarities in the experience of asthma between the South Asian and White British families, including limited understanding of asthma causes and triggers; confusion about the use of medications; uncoordinated care; lack of holistic discussions with healthcare professionals; and delays in receiving a clear diagnosis. No family had received an asthma plan. However, there were differences in experiences too, as South Asian families reported higher levels of stigma than White British families, had more difficulty in recognising severity of symptoms, and those with limited English faced additional barriers to receiving adequate information and advice about management due to poor communication support systems. South Asian children were more likely than White British children to feel embarrassed and to attribute physical activity as a trigger for asthma symptoms.

The MIA study points to a clear need to listen more systematically to the views, experiences and beliefs of marginalised communities in order to design tailored interventions that will be both effective and trusted. This would align with our broader understanding of the barriers socially excluded communities face accessing healthcare services, such as digital exclusion and low health literacy and highlights the importance of increased understanding in this area.

## 4. Conclusion

Our review found a reasonable body of qualitative research in the field of children and young people's asthma care, from which some clear themes emerge. Children and young people's most positive experiences of NHS care are when they obtain easy and quick access to specialist doctors and nurses who understand them, can communicate in terms they understand and can provide coordinated, developmentally-appropriate care. They want a clear, written action plan that is available to everyone who is caring for them and clarifies their medication dosage. And they want more information, advice and support so they can

better manage their condition themselves. Variations in care are preventing those most in need of services from receiving the high quality care they need, whilst a range of social factors can act as barriers to effective self-management.

It is hoped that these clear messages can help inform the co-development of more child- and young person-centred treatment pathways, models of care and self-management approaches that are based on a thorough understanding of children and young people's particular developmental life stage, preferences, thinking and behaviour.

However, this review has identified some significant gaps in our knowledge. We note that much of the published qualitative research has been conducted with children and young people of school age, sometimes alongside both their parents, whose views often differ from or influence the views of their children, and also the clinicians who are caring for them. It is important that we hear from children, young people, parents and professionals separately in future studies and research.

In particular, there has been a general lack of recent participatory research focussed on eliciting the views and experiences of older adolescents and young adults as independent users of healthcare services. Issues relating to effective transition from child to adult services as well as additional barriers to self-management such as the cost of prescriptions have been raised by older young people and need consideration. There is also a dearth of evidence on the specific views and experiences of young people from different marginalised groups. This includes a lack of evidence relating to diverse range of minority ethnic children, young people and families including for example African, Caribbean and Gyspy, Roma, Traveller communities.

Greater collaboration in future research initiatives between health academics and colleagues from youth work and social science disciplines would be valuable in order to understand the influence of a range of social determinants of poor asthma outcomes in children and young people.

## About the organisations undertaking this work

**The Young People's Health Partnership,** led by the **Association for Young People's Health,** is a consortium of six national youth and young people's health charities working to represent the interests of young people and young adults aged 10 – 25. We focus specifically on young people facing health inequalities.

**Friends, Families and Travellers** works on behalf of all groups of Gypsies, Roma and Travellers regardless of ethnicity, nationality, culture or background. We have strong roots in Gypsy, Roma and Traveller communities of all ages.

**The Race Equality Foundation** seeks to explore discrimination and disadvantage, and use that knowledge to help overcome barriers and promote race equality in health, housing and social care.

**The Royal College of Paediatrics and Child Health/RCPCH &Us** is the voice of children, young people, parents and carers for the college, created to actively seek and share their views to influence and shape policy and practice.

**VCSE Health and Wellbeing Alliance** is a partnership between voluntary sectors and the health and care system to provide a voice and improve the health and wellbeing for all communities. This work has been funded via the Health and Wellbeing Alliance.

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