



How have health systems policy responses to Covid-19 affected children with chronic illness in the UK?

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1. About this report

This report presents key findings from the first stage of an AHRC-funded research aiming to examine questions of health justice arising out of health systems policy response to Covid-19 pandemic for children with chronic illness. The first stage of the study looks at the changes in the delivery of and access to care for children and young people (CYP) with chronic illness and long-term conditions in the UK, as well as the health risks associated with these changes. Evidence gathered is based on findings from a scoping review of the literature, and feedback from healthcare professionals, including community paediatricians, consultants in sleep medicine, paediatric nephrology, paediatric neurology, paediatric respiratory medicine, and a consultant in neonatal intensive care.

Our scoping review aimed to understand the changes made to paediatric healthcare provision during the pandemic and their impact on the health and wellbeing of children and young people with chronic illness. Subsequently, a series of discussions with healthcare professionals and service managers in London hospitals were conducted to explore their views and concerns about the healthcare changes made and to understand how our initial findings from the literature aligns with their experiences.

1.1 What is this report for?

This report aims to provide evidence about the impact of health systems policy response to the Covid-19 pandemic on delivery of, and access to, healthcare for children with chronic illnesses in the UK, with regard to their physical and mental health. It explores what is known about these changes, focusing on selected health conditions that emerged from our scoping review. It considers:

- The nature of health system changes during Covid-19, including changes to primary and secondary care provision and emergency services.
- The extent to which these changes affected children with long-term conditions, such as the ability to access medication, impact of telemedicine, and delays in diagnosis.
- The concerns of healthcare professionals both around the impact on children with long-term conditions and on child health and wellbeing more generally.

1.2 Who is it for?

This report offers findings of practical interest to all those involved in decisions regarding healthcare delivery for children with chronic illness. Healthcare professionals and managers at different levels helped to develop the material.

Decisions about the delivery of services during and after the pandemic should be guided both by research evidence and ethical considerations regarding standards of care and fair allocation of medical resources. This report adds to the discussion about how to address inequalities in access to care and health outcomes for children with chronic illness in times of crisis while protecting the health of the wider community.

Collecting evidence is important to answer the following questions:

1. What findings are of most practical use and moral importance to those delivering and organising child health services?
2. What are the standards that child health services should deliver in the aftermath of the pandemic?
3. How can these findings inform future emergencies of this kind?

2. Scoping review

2.1. Why we did the scoping review

The UK response to the Covid-19 pandemic saw healthcare resources redeployed to respond to local Covid-19 challenges. Government instructions that GPs conduct remote triage care to patients, and advice to the public to stay at home wherever possible, had a significant effect on the provision of and access to care, particularly for CYP with chronic conditions [1]. Our research looked at how the health systems and policy response to the Covid-19 pandemic affected children with long-term conditions in the UK. Our findings will inform a further piece of work designing an ethical framework that considers the needs of CYP with chronic illness in the prioritisation processes required in the pandemic context and beyond.

2.2 What we did

Our purpose was to identify and understand emerging evidence, regardless of study design, therefore a scoping review rather than a systematic review was considered optimal [2]. Two databases, PubMed and PsycINFO, were searched for publications between March 2020 to August 2021, and grey literature was collated manually. Keywords relating to Covid-19, child healthcare, chronic illness and impact were used. Two queries were used in each database, the first identifying papers that focused on primary care/ hospital records and projected health outcomes and the second search focusing on qualitative research on patient and/or carer views (for more details regarding our research methodology see: Lignou S, Greenwood J, Sheehan M, Wolfe I. Changes in Healthcare Provision During Covid-19 and Their Impact on Children With Chronic Illness: A Scoping Review. *Inquiry*. 2022 Jan-Dec;59:469580221081445. doi: 10.1177/00469580221081445. PMID: 35345920; PMCID: PMC8969043.)

Some methodological considerations and limitations need to be taken into account. Out of the 32 articles included in the analysis, only 14 of them were specifically on child chronic illness in the UK. Within these, the conditions mainly discussed were asthma, cancer, diabetes, epilepsy and inflammatory bowel diseases, and some neurodevelopmental and mental health conditions.

2.3 What we found out

Chronic Health Conditions

Asthma

- **Impact on care**
 - There were fewer emergency department presentations of severe asthma during the pandemic [3].

- **Impact on physical health**
 - The decrease in asthma severity is likely due to: better adherence to medical routines, parents' increasing surveillance, reductions in air and road traffic, decreased interaction between children, restricted travel, shielding and social distancing [3].

Diabetes

- **Impact on care**
 - Telemedicine was reported to be the standard treatment for CYP with diabetes [4].
 - Both emergency and routine care was provided via phone or video call but the efficacy of this virtual support remains to be seen [5].
 - One third of UK A&E paediatricians reported witnessing delays in diagnosis of diabetes mellitus or diabetic ketoacidosis [1].
- **Impact on physical and mental health**
 - Diabetes patients are two to three times more likely to have depression and poor mental health during the pandemic which may have had a negative impact on diabetes control and blood glucose levels [6].

Epilepsy

- **Impact on care**
 - Many CYP with epilepsy and caregivers of CYP with epilepsy reported difficulties acquiring prescriptions and contacting primary healthcare physicians [7].
 - Paediatric surgery fell to 12–20% of normal activity in some areas of the country [8].
 - Many CYP had their electroencephalogram (EEG) and magnetic resonance imaging (MRI) appointments cancelled [7].
- **Impact on physical health**
 - Telemedicine may have decreased accuracy of diagnoses [9].
 - Increased seizure severity was reportedly due to difficulties accessing medicine, reduced access to health professionals and the sleep problems, mood changes and stress related to the pandemic [10]. High numbers of patients required emergency care [7].

Cancer

- **Impact on care**
 - There was a large decrease in referral rates for cancer [11].
 - The reliance on telehealth may have caused delayed or missed diagnosis [11].

- **Impact on physical health**

- It is estimated there will be 3291 - 3621 avoidable deaths of both adults and children from five cancer types in the 5 years after diagnosis compared with the pre-pandemic period [11].
- An additional estimated 59,204 – 63,229 years of life could be lost [11].

Inflammatory Bowel Disease

- **Impact on care**

- For CYP with inflammatory bowel disease there was a lack of face-to-face appointments, difficulties in continuing day-case infusions and problems reviewing patients or performing routine monitoring of the condition [12].
- There was reduced use of endoscopy in 90% of UK centres [12].
- Over 50% of CYP were diagnosed without the usual histological and endoscopic assessment [12].

Neurodevelopmental conditions

- **Impact on care**

- Telephone consultation was the most commonly used method of remote contact, with 98% of healthcare practitioners reporting its use [13].
- There was an increase in online resources designed for CYP with emotional, behavioural, neurodevelopmental and intellectual disorders but CYP with autism and other neurodevelopmental conditions may have found virtual appointments difficult to access [13].
- There was redeployment of staff from community child health (CCH) services and therefore restrictions to direct face-to-face contacts. Key clinical activities were limited, non-urgent referrals were deferred and CCH teams experienced significantly increased waiting lists [13].

Mental health conditions

- **Impact on care**
 - GP contact levels between March – July 2020 were below the average of the previous 3 years [14].
 - Digital healthcare increased access for some CYP but may have led to missed or delayed diagnoses.
 - 26% of CYP with existing mental health needs were unable to access psychological support [15].
- **Impact on physical health**
 - Unmet mental health needs may impair the health and wellbeing of CYP with chronic illness [7].
- **Impact on mental health**
 - Having difficult health-related conversations virtually impact patient mental health [9].

General considerations regarding children's physical health

Guidance about shielding, as well as the prioritisation of the pandemic response by the Government and health services, meant that many people did not seek healthcare or had difficulty accessing it [7]. Changes in the delivery of and access to healthcare significantly affected children and young people with chronic illness during the Covid-19 pandemic. Parents' reluctance to seek healthcare during the pandemic indicates that many children remained at home with serious pathologies [1]. There was significant unmet need among children with chronic conditions, which could lead to increased morbidity and mortality across various physical health conditions [1, 16].

Children's social care and mental health

In addition to the reduction in contact with healthcare professionals, pandemic restrictions meant that vulnerable children missed their usual contact with education and social care professionals [18]. It is believed that many CYP may have been experiencing maltreatment or domestic violence unknown to professionals [18]. The need for CYP to access psychological support increased during the pandemic. Difficulty accessing this support is particularly concerning for children with chronic health conditions as they are more likely to experience psychosocial difficulties [15].

A wider look

Significant impact of the pandemic on health systems was reported internationally including in the US, Asia and Europe particularly for epilepsy, asthma and diabetes [9, 4, 6].

Research conducted with paediatric epilepsy professionals predominantly in Asia and North America reported significant restrictions in face-to-face appointments. More than half said that they were not able to admit any child for pre-surgical assessment and one third reported that all surgeries were put on hold [9].

Research with asthma experts in Asia, North America and Europe reported that almost half of centres did not accept new patients, and between 39-60% of centres ceased face-to-face appointments [19].

A survey completed by diabetes practitioners in 75 countries found increased incidence of DKA among patients and a significant number reported delayed diagnosis and admission to hospital [6]. Another review examining the psychosocial impact of the pandemic on children and young people worldwide cited many significant stressors, including heightened health anxiety, disrupted routines, school closures, family stress and risk of domestic violence and reduced physical and psychosocial support [15].

2.4 Why our results are important

We can see from our initial investigation that only a small number of studies exploring children's health needs during the pandemic have been conducted, signifying that children's needs have not been adequately considered in evaluating health systems policy responses to the pandemic. Considering children's needs when evaluating health systems policy response is an important step to designing more effective, resilient and fair health systems. Further research is needed to ensure that children's health is properly considered in the response to health emergencies.

3. Engagement with stakeholders

A number of questions were formulated to enable healthcare professionals and managers to comment on changes in health services' provision in their organisations, and to identify tensions and dilemmas they experienced during the pandemic.

The following questions were asked:

1. What was the change and how was the decision made? Was the change determined within the service or organisation or imposed from the government?
2. How does that change fit in with other objectives set for the organisation/unit/hospital?
3. Who was involved in these decisions and based on what criteria were they made?
4. What patient groups were/are affected?
5. What problems were expected and were any initiatives/strategies taken to address them?
6. What are your concerns about these changes?

3.1 Making sense of the pressures on services during the pandemic

Our scoping review found that the prioritisation of the Covid-19 response led to significant changes to paediatric healthcare provision, which had considerable impact on children and young people's health and wellbeing. Through subsequent discussion with paediatric healthcare professionals in London, we reached a greater understanding of what changes were required within settings, what considerations were taken into account and how these changes impacted healthcare professionals and their ability to provide care for children and young people.

When asked to describe what changes needed to be made and how these decisions were made, healthcare professionals and managers referred to the instruction from NHS England to cease all face-to-face activity in the first wave of the pandemic. One community paediatrician reported that their directorate initially stood down services for 80% of the population but kept them open for the most vulnerable 20%, however only a small number remained face-to-face. Healthcare professionals reported community teams being redeployed to acute adult services. NHS England, Trusts and Clinical Group Executives primarily made the decisions relating to changes in provision. Some professionals stated that they were able to make more local decisions when services reopened but during the second national lockdown, beginning on 5th November 2020, they still experienced pressure to offer staff to redeployment.

Many of the healthcare professionals we spoke to reported competing priorities during the pandemic. A consultant in paediatric sleep medicine stated that they had two different streams of patients, those referred for a diagnostic sleep study and those seen in clinic, who were impacted differently and had differing needs. The different impact on these patients was not something that was captured in our literature review.

The professionals we spoke to expressed concern about pressure from central hospital teams to keep a significant proportion of appointments virtual, resulting in an “increased risk of harm and sub-optimal care for young people”, as described by one paediatric consultant. They expressed concern that it is difficult to predict which children or young people are more likely to be vulnerable from the lack of face-to-face care.

3.2 Key concerns among healthcare professionals

Certain factors were cited by the professionals we spoke to as having had an adverse impact on patient care:

- The closure of schools, where community paediatricians deliver care, and nursing for children with neurodevelopmental conditions, meant reduced access to healthcare and less frequent review referrals (Clinical Director, Community Paediatrics).
- The move to virtual clinic models has presented a mixture of both positive and negative impacts for patients (Consultant in sleep medicine).
- Rheumatology and neuroinflammatory patients experienced significant changes in their treatment appointments. For example, where infusions had been required every 4 weeks, children’s treatment plans were altered to require only 6-monthly treatment. This may have affected susceptibility to infection (Consultant in paediatric neurology).
- The care of a small number of long-term ventilated patients with very high needs was significantly affected. Ventilation technology is commissioned at national level but these teams were occupied with Covid-19 (Consultant in paediatric respiratory medicine).
- Virtual outpatients and overnight sleep studies were difficult to do virtually, so alternate virtual with face-to-face consultations were initiated (Consultant in sleep medicine).
- Face-to-face assessments for autism and developmental concerns were ceased. While virtual appointments were accessible for some children, some were not able to access this support, and face-to-face assessment is considered important for accuracy.

- Additionally, children with neurodisabilities were not receiving their usual school-based activity and a decline in strength and ability in children with disabilities has been noted (Clinical Director, Community Paediatrics).
- Patients suffered, and are still struggling with, their mental health.
- There were delays in surgery, for example kidney transplantation and increased need for dialysis. Professionals reported that resources were stretched (Paediatric nephrology).
- There was a high impact on care delivery of children in Paediatric Intensive Care Units. The impact of this may be apparent for some time (Consultant in neonatal intensive care).
- There were concerns around equipment management and the regression of children with disabilities due to decreased activity and participation. There was increased need for surgery and investigations were also delayed (Clinical Director, Community Paediatrics).

3.3 Common concerns among healthcare professionals

Most of the professionals we spoke to were concerned about the following issues:

Safeguarding children and young people. During the first wave of the pandemic, professionals raised concerns that safeguarding referrals would fall. This concern was borne out in the data that followed. The fall in referral rate was considered to be due to schools closing, health visiting services being conducted virtually, and parents not seeking advice. The move to virtual appointments limited the efficacy of risk assessments of children and there is concern that many children remain 'hidden' from view. Subsequently services have seen a significant increase in referrals, likely due to a backlog of demand (Clinical Director, Community Paediatrics).

The impact of telemedicine. Many of the professionals we spoke to had concerns about the use of telemedicine and its efficacy. A consultant in paediatric nephrology reported that the move to telemedicine affected outpatient services where they needed to do remote testing. Some blood tests were conducted at children's homes and in hubs where clinicians could meet their patients. A consultant in paediatric respiratory medicine said that families appeared to value virtual appointments, provided they also received some face-to-face care.

3.4 In response to specific challenges identified from the literature:

Public messaging and shielding. Our research found that many children and young people did not access the healthcare that they required, partly due to shielding directives from the Government [1]. The views of paediatrics professionals aligned with this. They reported that when the pandemic first hit there was a long list of vulnerable children who were asked to shield. This meant health professionals had even more limited access to this highly vulnerable populations. They reported that this list was subsequently modified.

Telemedicine. Based on the results of our review telemedicine was the standard treatment for CYP with diabetes, with both emergency and routine care provided via phone or video call [5]. One third of UK A&E paediatricians reported witnessing delays in diagnosis of diabetes mellitus or diabetic ketoacidosis (a medical emergency), likely due in part to reliance on virtual consultations [1]. Another finding was that diagnosis of epilepsy and cancer may have decreased in accuracy and efficiency due to telemedicine [9, 11]. The efficacy of this virtual support remains to be seen, a view supported by the health professionals we spoke to.

Our scoping review reported concerns among healthcare professionals about the use of telemedicine with children and young people with neurodevelopmental difference [7]. While there was an increase in online resources for this population, children with autism and other neurodevelopmental conditions may have found virtual appointments difficult to access [13]. The views of a clinical director in community paediatrics aligns with these findings. They reported that face-to-face autism and developmental assessments were ceased, but telemedicine was not accessible or appropriate for all children and young people. However a consultant in paediatric respiratory medicine said that some of the weaknesses of existing virtual systems will be ameliorated by new technologies such as remote monitoring of physiology and adherence to healthcare routines but reported that there have been multiple barriers and delays to these developments.

Based on the findings of our review, telehealth improved access to services for many children but some communities have been under-served for reasons including language barriers and digital disparities [17]. In our discussions with healthcare professionals challenges regarding unequal access to telehealth were not mentioned, rather the focus was on effectiveness of telehealth as a means of delivering assessments and care.

Safeguarding. In addition to the reduction in contact with healthcare professionals, pandemic restrictions meant that vulnerable children missed their usual contact with education and social care professionals. Our scoping review reported that many children and young people may have been experiencing maltreatment or domestic violence unknown to professionals [18]. The need for CYP to access psychological support increased during the pandemic and difficulty accessing this support is particularly concerning for children with chronic health conditions who are more likely to experience psychosocial difficulties [10, 6]. The professionals we spoke to concurred with these safeguarding concerns, with the closure of schools, lack of face-to-face health visiting, and parents reluctant to seek healthcare advice cited as causes.

Asthma. Results of our review indicated that there were fewer emergency department presentations of severe asthma during the pandemic, likely due to: better adherence to medical routines, parents' increasing surveillance, reductions in air and road traffic, decreased interaction between children, restricted travel, shielding and social distancing [3, 20]. Interestingly, an opposing view was given by a Consultant in Paediatric Respiratory Medicine who said that while many people with asthma experienced less severe symptoms, there is a subgroup of complex patients who "spiralled out of control in the last 18 months". They reported that often these were patients with co-morbidities such as "breathing pattern disorder, anxiety, social inequalities and safeguarding issues and virtual appointments were not adequate to pick up early signs of deteriorating health or family disengagement."

3.5 What worked?

Our review found that telemedicine was effective in providing support to many children and young people with existing mental health difficulties who were unable to access face-to-face psychological support during the lockdown [21]. Some of the professionals we spoke to reported that telemedicine worked well in some cases. One sleep expert reported that it was difficult to conduct overnight sleep studies virtually, however they did see some positive impacts of virtual appointments for some patients. A paediatric neurology consultant said that outpatient appointments to assess seizure control worked reasonably well virtually.

3.6 New findings

Discussion with healthcare professionals providing new findings not reported in our scoping review.

- Decisions about service closures were made by NHS England with little service input, however during the second wave of the pandemic more decisions could be made at a local level.
- Our research showed that children's needs were not adequately considered in the response to the pandemic. A Clinical Director of community services reported that it was difficult to balance the needs of children with the national messaging. Professionals endorsed the need to take a different approach for children's community services but they did not "appear to have weight in decision-making at the point it came out." We learnt that a letter from professional bodies to ministers was sent in the winter of 2020, requesting that children's therapists would not be redeployed in the next wave of the pandemic.

4. Policy implications

We have gathered evidence about changes to the delivery of healthcare for children with chronic conditions, and the impact on physical and mental health, with a view to creating an ethical framework within which the impact on children's health is properly considered in the response to health emergencies.

Our research shows that the response to the pandemic had a significant impact on the provision of child healthcare in the UK. However, the relatively small number of studies exploring the impact of health systems changes on children during pandemic suggests that their needs require more careful consideration within the evaluation of the UK pandemic response. The lack of research into child health does not only apply to the subject of Covid-19 but is a wider problem [22] suggesting the potential of bias in healthcare planning and the development of information technology. More research is needed to understand the gaps in access to timely diagnosis and effective treatment and the impact of this on paediatric patients. Understanding the impact on children's health and wellbeing is a vital step towards a more effective and equitable health system response to future emergencies.

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