Changes in Healthcare Provision During Covid-19 and Their Impact on Children With Chronic Illness: A Scoping Review

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Abstract
This paper provides an overview of the evidence around how the health systems and policy response to the Covid-19 pandemic affected children with long-term conditions in the UK. We conducted a scoping review guided by the PRISMA-ScR Checklist. The PubMed and PsycINFO databases (2019-August 2021) were searched and screened for papers (of any design) by 2 reviewers independently. The electronic database search was supplemented by manual searching. A total of 32 papers were identified, including studies on UK paediatric populations, studies on chronic illness in the UK, and international studies on chronic illness and children (including data from the UK). Most studies focussed on epilepsy, cancer, diabetes or asthma. Three categories of impact were identified: (a) impact of policy response on the delivery of and access to child healthcare (b) impact of innovative practice on children’s physical and mental health (c) impact of service restrictions on children’s physical health. Our results showed that policy response to the pandemic significantly affected healthcare provision for children with chronic illness in the UK. However, the specific assessment of the impact of service restrictions and innovative practice on children’s health and wellbeing is limited. Future research is required to fill knowledge gaps on changes in access to effective diagnostic and treatment investigations and their impact on a range of paediatric patients during the pandemic.

Keywords
telemedicine, paediatrics, health systems, covid-19, chronic illness, policy, mental health, child healthcare services

Introduction
Children with chronic illness and long-term conditions require both planned and urgent care, over long periods of time. The quality of this care depends on established therapeutic relationships and the interaction across health services, such as inpatient and outpatient health and social care services.¹ The multiple and complex needs that characterise this group of children also renders them particularly vulnerable to changes in the delivery of care.

Pandemic restrictions were introduced in the UK on 23rd March including social distancing and shielding for those with acute physical conditions.²,³ National Health Services (NHS) around the country adjusted healthcare delivery policies, affecting all populations, and children in specific ways. Many Tier 1 paediatric staff were redeployed and paediatric inpatient space was lost to adult services.⁴ Based on a nationwide survey by the Royal College of Paediatrics and Child Health (RCPCH), up to 90% of services reported a decrease in inpatient activity at the beginning of April, falling

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to 49% by 3rd July. Only 9% reported an increase in inpatient activity compared to the same time last year.4

The effects of the pandemic are expected to dominate healthcare delivery in the UK for at least the next few years.5 It is therefore crucial to understand the nature and degree of impact of health system changes on children with long-term conditions.

This scoping review aims to explore the currently available evidence on how the health systems policy response to Covid-19 has impacted children with chronic conditions in the UK.

Methods

As our purpose was to identify and map emerging evidence in a fast changing situation regardless of study design, a scoping review rather than a systematic review was preferable.6 The review was conducted according to the PRISMA-ScR.7 The research was formulated around the PICO model: the Population of interest was children with chronic conditions; the Intervention was the emergence of the Covid-19 virus and subsequent changes to healthcare provision, which were Compared with pre-pandemic standard of care. We examine the impact and outcomes of these changes to healthcare provision on children with chronic conditions.

Search Strategy

The scoping review was guided by the following question: ‘How have health systems policy responses to Covid-19 affected children with chronic illness in the UK?’ Two databases, PubMed and PsycINFO, were searched from March 2020 to August 2021. Two queries were used in each database, a broad query focussed on primary care/hospital records and projected health outcomes and a specific query focussed on qualitative research about healthcare professionals and patients/carers views.

Keywords relating to Covid-19, child healthcare, chronic illness and impact were used. The search strategy [Appendix 1] was drafted by SL with the help of an experienced librarian and further refined through team discussion. Limits on number of results and other filters were not set.

Study Inclusion and Charting of Data

In the first instance, two of the authors (SL and JG) screened the article titles and abstracts independently and selected articles using inclusion criteria [supplementary material] to account for any impact reported on Chronic Health Conditions (CHC) in the UK during the pandemic. The remaining articles were then screened in full by the 2 authors independently. Articles were selected based on the following criteria. Inclusion criteria are as follows: UK studies on Covid-19 and paediatric population, UK studies on Covid-19 and patients with chronic illness, UK studies on Covid-19 and health services, international studies including data from the UK on Covid-19 and chronic illness. Exclusion criteria: UK studies not related to Covid-19 and chronic illness or health systems, international studies on adult and child populations and Covid-19 not related to chronic illness, international studies on paediatric chronic illness and Covid-19 not referring to the UK.

Disagreements on study selection and data extraction were resolved by consensus and discussion with the other authors (MS and IW) when required.

The electronic database search was supplemented with manual searching. Reference lists of the final articles from the database search were hand-searched by SL and JG and
| Author, Year                        | Setting                        | Constituent countries | Study design                  | Study population | Sample size | Age range | Type of chronic illness | Type of impact/impact theme | Major outcomes                                                                 |
|------------------------------------|--------------------------------|-----------------------|-------------------------------|------------------|-------------|-----------|------------------------|----------------------------|--------------------------------------------------------------------------------|
| Ashikkali, Carroll & Johnson (2020)| Emergency and routine care     | UK                    | Literature review             | UK, paediatric   | N/A         | Unspecified          | Physical and mental health conditions | A4, C1                      | There was a decrease of over 30% in the cases of children presenting to the paediatric emergency department by March 2020 which was maintained into the summer. This may have meant reduced unnecessary attendance to the department however a lack of treatment could also put children with serious pathologies at greater risk. |
| Ashton, Batra & Coelho et al. (2020)| Paediatric Gastroenterology   | UK, China, South Korea| Literature review             | International, paediatric | N/A         | Unspecified          | Inflammatory bowel disease          | A2, A4                  | Healthcare professionals could not provide the same level of diagnostic care and ongoing management to patients with inflammatory bowel disease during the pandemic. |
| Ashton, Kammermeier & Spray et al. (2020)| Tertiary paediatric IBD centres | UK                    | Survey                        | UK, paediatric   | 20 tertiary paediatric IBD centres | Unspecified          | Inflammatory bowel disease          | A4, C1                  | Diagnostic IBD practice has been severely impacted by COVID-19. More than 50% of new diagnoses did not include endoscopy. |
| Cameron, Hausari & Hollingworth et al. (2020)| Routine healthcare           | UK                    | Survey                        | UK, adults and children | 522 adult respondents (members of general public within borough of Tower Hamlets) | Unspecified          | Physical and mental health conditions          | C                        | Covid-19 impacted many areas of child healthcare including newborn screening, developmental checks, immunisations and health visiting. There was an ethnic disparity with White respondents more likely to access reviews and immunisations than other ethnic groups. |
| Charlesworth, Bold & Pal (2021)    | Emergency care                | UK                    | Retrospective observational cohort study | UK, paediatric | Unspecified | 0-15       | Infective disease, sequelae of infective illness, respiratory disease | C3                      | Public health measures significantly altered paediatric presentations. Oxfordshire hospitals saw a 58% reduction in ED attendances/inpatient admissions. Missed diagnoses were predominantly seen in infection-related illnesses. |

(continued)
| Author, Year                  | Setting                                      | Constituent countries                                                                 | Study design                        | Study population      | Sample size | Age range | Type of chronic illness | Type of impact/impact theme | Major outcomes                                                                 |
|------------------------------|----------------------------------------------|----------------------------------------------------------------------------------------|-------------------------------------|-----------------------|-------------|-----------|-------------------------|-----------------------------|--------------------------------------------------------------------------------|
| Creese, Taylor-Robinson & Saglani, et al. (2020) | Primary Care                                 | UK                                                                                     | Literature review                   | UK, pediatric         | N/A         | Unspecifed            | Asthma                     | C1, C3                                                                       | There were fewer severe asthma presentations in CYP to emergency room during the pandemic. School closures and social distancing meant fewer triggers from respiratory infection. Caregivers’ heightened concern for children with asthma likely improved adherence to medication and reductions in air and road traffic led to the reduction in some air pollutants across the UK. |
| Elbarbary, Jeronimo dos Santos & de Beaufort et al. (2020) | Diabetes centres                            | 75 countries. Majority from UK (35: 16.3%), USA (20: 9.3%) and India (15: 7%)           | Survey                              | International, pediatric | 303 respondents (healthcare professionals) | 0-16       | Diabetes              | A2, A5                                                                    | Healthcare professionals adapted to the pandemic by implementing telemedicine. One fourth of professionals reported delays in diagnosis and an increased rate of Diabetic ketoacidosis. The pandemic had an important impact on family’s behaviour that might have lead to increase in DKA presentation. |
| Forde, Arente & Ausili et al. (2021)            | Specialist, community or in-patient settings | Belgium; Bosnia and Herzegovina; Croatia; Cyprus; Czechia; Denmark; Estonia; Finland; France; Germany; Greece; Ireland; Italy; Latvia; Malta; Netherlands; Norway; Poland; Portugal; Romania; Spain; Sweden; Switzerland; Turkey; Ukraine; United Kingdom (UK). | Survey                              | International, adults and children | 1829 respondents (diabetes nurses) | Unspecifed            | Diabetes                     | C1, B                                                                      | There was an increase in both physical and psychological problems in patient populations during the pandemic and clinical diabetes services were significantly disrupted. |
| Hartmann-Boyce, Morris & Goyder et al. (2020)  | Routine healthcare                           | Multiple, including UK, US, China                                                       | Literature review                   | International, adults and children | N/A         | Unspecifed            | Diabetes                     | B                                                                          | After social distancing and shielding guidance was issued, primary and secondary care began to provide both emergency and routine follow-up on the phone or via video consultations. This also included support for mental health. |
| Author, Year         | Setting                              | Constituent countries | Study design               | Study population | Sample size | Age range          | Type of chronic illness | Type of impact/impact theme | Major outcomes                                                                 |
|---------------------|--------------------------------------|-----------------------|----------------------------|------------------|-------------|--------------------|-------------------------|---------------------------|--------------------------------------------------------------------------------|
| Hefferon, Taylor & Bennett et al. (2020) | Emergency care and community paediatrics | UK                    | Literature review          | UK, paediatric   | N/A         | Unspecified paediatric population (0-18) | Acute physical conditions and mental health conditions | A2, A3, A5 | Disruptions to planned outpatient visits, operations or healthcare may have led to increased morbidity for some children. These changes have also led to increased anxiety for families. |
| Isba, Edge & Jenner et al. (2020) | Emergency care                       | UK                    | Retrospective cohort study | UK, paediatric   | Unspecified | <16                | Physical conditions and safeguarding | A3           | There was a decline in paediatric emergency department attendances meaning many children may be at home with serious pathologies or illnesses. |
| Jia, Bao & Yi et al. (2020) | Paediatric respiratory clinics       | UK                    | Interviews                 | UK, adults and children | 16 (caregivers) | Caregivers of children <14 | Asthma | C | Six main themes identified: (1) improved asthma control; (2) decreased willingness to seek medical care; (3) increased adherence to treatment; (4) coping strategies for changes caused by the pandemic; (5) a new opportunity and 6) managing new challenges in asthma control. |
| Kelly & Firth (2020) | Emergency care                       | UK                    | Literature review          | UK, adults and children | Unspecified | Unspecified         | Gastroenteritis, respiratory conditions | C3           | On 14 May 2020 A&E visits were 57% lower in the previous month compared with April 2019. A&E visits across all unit types dropped by 27% in April, but there was a greater decrease in minor A&E units than in major A&E units. |
| Kursumovic, Cook & Vindrola-Padros et al. (2021) | Anaestheia and critical care         | UK                    | Survey                     | UK, adults and children | 470 (healthcare professionals) | Unspecified (child and adult population) | Non-cancer elective, cancer | A4           | There was increased systemic pressure on anaesthetic and peri-operative services due to the demand of the pandemic on critical care. |
| Lynn, Avis & Lenton et al. (2021) | Emergency care and paediatric assessment units | UK                    | Survey                     | UK, paediatric   | 4075 (paediatric consultants) | 0-16            | Diabetes, sepsis, malignancy | A3, C1 | Diabetes mellitus was the most common delayed presentation, as well as sepsis and malignancy. There were nine deaths where delayed presentation was considered a contributing factor, resulting mainly from sepsis and malignancy. |
| Author, Year                        | Setting | Constituent countries | Study design                     | Sample size | Age range | Type of chronic illness | Type of impact/impact theme | Major outcomes                                                                 |
|------------------------------------|---------|-----------------------|----------------------------------|-------------|-----------|-------------------------|-----------------------------|--------------------------------------------------------------------------------|
| Mansfield, Mathur & Tazare et al.  (2021) | Primary care | UK                    | Statistical analysis             | UK, adults and children | Jan 1 2017: 9,863, 903 (population included in analysis) | 11+ | Acute physical and mental health conditions | A1 | Primary care contacts for almost all conditions examined dropped considerably after Covid-19 restrictions were implemented, particularly for diabetic emergencies, depression and self-harm. |
| Maringe, Spicer & Morris et al.    (2020) | Primary and secondary care | UK                    | Population-based modelling study | UK, adults and children | 93,607 (patients) | Unspecified (child and adult population) | Cancer | A4, A5, B, C2 | Between 3291-3621 avoidable deaths would have occurred in 5 years after diagnosis across four tumour types. It is predicted that between 59,204-63,229 years will be lost due to delays in cancer diagnosis alone as a result of the COVID-19 lockdown in the UK. |
| Mulholland, Wood & Stagg et al.    (2020) | Emergency care and emergency and planned hospital admissions | Scotland                | Statistical analysis             | UK, adults and children | Unspecified 0-85+ | Paediatrics (medical), Paediatrics (surgical) | A3 | There was a sharp drop in A&E attendances as well as planned hospital visits. Children aged under 15 years were particularly affected by reduced access to emergency care, both in terms of attendances and admissions. |
| Ogundele & Ayyash (2021)           | Community Child Health Services | UK                    | Literature review and scoping survey | UK, paediatric | 62 responses to survey (healthcare professionals) | Unspecified paediatric population (0-18) | Neurodevelopmental/ emotional/behavioural disorders | A2, A4 | Restrictions in face-to-face contacts and redeployment of staff from Community Child Health (CCH) services meant that many core clinical activities were limited and most new referrals were kept on hold except for urgent services. Many services greatly increased their telemedicine capacity. |
| Papadopoulos, Custovic & Deschildre et al. (2020) | Paediatric asthma clinics | 27 countries from 5 continents; Africa, Asia, Americas, Europe, and Oceania | Survey | International, paediatric | Ninety-one respondents (carers for approximately 133,000 children with asthma) | Unspecified paediatric population (0-18) | Asthma | A4, C1 | Outcomes for some children with asthma may have improved, possibly due to increased adherence and/or reduced exposures. Asthma services responded to the pandemic by conducting virtual encounters instead of physical appointments. |

(continued)
| Author, Year | Setting | Constituent countries | Study design | Study population | Sample size | Age range | Type of chronic illness | Type of impact/impact theme | Major outcomes |
|-------------|---------|-----------------------|--------------|-----------------|-------------|-----------|-----------------------|---------------------------|----------------|
| Reilly, Muggeridge & Cross (2021) | Routine care | Scotland | Survey | UK, paediatric | 201 (young people: 71 and caregivers: 130) | Young people (12-25) Caregivers (0-25) | Epilepsy | B, C1 | The pandemic and the associated restrictions have negatively impacted young people with epilepsy. Participants reported increases in seizures, reluctance to go to hospital and cancelled investigations. The wider psychosocial impact includes increases in child and caregiver mental health problems. |
| Roland, Harwood & Bishop et al. (2020) | Emergency care | UK | Multi-centre surveillance | UK, paediatric | 1349 respondents (healthcare professionals) | <16 | Soft tissue injuries or fractures but no other specific pathologies | A3, C3 | 93.5% of parents were felt not to have delayed presentation. Delayed presentation was relevant in 3% of cases. In 8% of cases, advice from a medical professional or NHS 111 was considered to have resulted in delay. |
| Serlachius, Badawy & Thahar (2020) | Emergency and routine care | UK, Ireland, Germany, Canada, Australia, China, Italy, Singapore, New Zealand, Austria. | Literature review | International, paediatrics | Unspecified | Unspecified paediatric population (0-18) | Chronic health conditions | B | Challenges identified include: increased anxiety, disrupted routines, academic and social stresses associated with school closure, increased risk of domestic violence and abuse, and reduced access to physical and psychosocial support. Opportunities include: reduced academic and social stress, increased time with families, reduced access to substances, easier access to health care using technology, and opportunities to build resilience. |
| The Royal College of Paediatrics and Child Health (2020) | Emergency and routine care | UK | Survey | UK, paediatric | 30% to 53% respondents per week (healthcare professionals) | Unspecified paediatric population (0-18) | Diabetes, mental health conditions, sepsis | A3, C1, C2 | Paediatric care activity across all areas decreased or was unchanged compared to the same week the previous year, causing many healthcare professionals to report concern about the wellbeing of the children they weren’t seeing. |
| Thornton (2020) | Emergency care | UK | Literature review | UK, adults and children | Unspecified (child and adult population) | Pneumonia, cardiac, myocardial ischemia, and gastrointestinal conditions | C3 | In the week after lockdown (March 23-29) attendance at A&E was down 25% on previous week. |
Table 1. (continued)

| Author, Year                     | Setting                                                                 | Constituent countries                                                                 | Study design          | Study population                                                | Sample size | Age range | Type of chronic illness | Type of impact/impact theme | Major outcomes                                                                 |
|---------------------------------|-------------------------------------------------------------------------|----------------------------------------------------------------------------------------|-----------------------|-----------------------------------------------------------------|-------------|-----------|------------------------|--------------------------------|--------------------------------------------------------------------------------|
| Thorpe, Ashby & Hallab et al.   | Specialist care and unplanned/ emergency hospital admissions            | UK                                                                                     | Survey                | UK, adults and children                                        | 463 respondents (people with epilepsy: 316 and caregivers on behalf of a person with epilepsy: 147) | <18–65 Epilepsy              | A1, A4, B, C3                       | Responses included reported change in seizures, mental health difficulties and sleep disruption. Participants reported finding it difficult to take medication on time. There were difficulties accessing medical services and cancelled appointments. |
| Watson, Pickard & Williams et al. (2021) | Primary and secondary care                                                | UK                                                                                     | Semi-structured interviews | UK, paediatric (caregivers)                                      | 15 participants (caregivers) | Caregivers (25-60) of children (0-16) | Physical health conditions | A1, B                              | Delays in seeking care occurred predominantly due to fear, community perception and experience and media portrayal. Reported delays in reaching care were focused on availability of services and access to primary care. |
| Williams, Jenkins & Ashcroft et al. (2020) | Primary care                                                            | UK                                                                                     | Retrospective cohort study | UK, adults and children                                         | 241,458 (patients) (child and adult population) | Unspecified | Common mental health problems, cardiovascular and cerebrovascular disease, type 2 diabetes and cancer | A5, B, C2, C3                     | Diagnoses of common conditions decreased substantially between March and May 2020. This suggests a large number of patients have undiagnosed conditions. |
| Williams, Macrae & Swann et al. (2020) | Primary care, emergency department and emergency hospital admissions     | Scotland                                                                               | Retrospective cohort study | UK, paediatric (unspecified)                                    | Unspecified (paediatric population) (0-18) | 0-14 Respiratory conditions, neurological conditions, injury, poisoning | A1, A3, C1, C2, C3              | There was an almost two-thirds reduction in unscheduled primary care during the study period compared with the same weeks in 2016–19 and also a reduction in emergency department attendances. |
| Wirrell, Grinspan & Knupp et al. (2020) | Paediatric Epilepsy Centres and Child Neurology Centres                  | 49 countries from 6 continents including Asia (40.6%), North America (36.8%)           | Survey                | International, paediatric                                       | 212 respondents (paediatric neurologists) | Unspecified paediatric population (0-18) | Epilepsy | B, C1                             | Findings included an increase in the use of teledermatology, decreased EEGs, changes in treatments of infantile spasms, and cessation of epilepsy surgery. |
| Wise (2020)                     | Emergency care and paediatric assessment units                           | UK                                                                                     | Survey                | UK, paediatric (paediatric consultants)                         | 243 respondents (paediatric consultants) | Unspecified paediatric population (0-18) | Diabetes, sepsis, malignancy | C1, C2                             | Delays in attending the emergency department during the pandemic may have contributed to the deaths of nine children. |
| Young Minds (2020)              | Psychological support services                                          | UK                                                                                     | Survey                | UK, paediatric (young people)                                   | 2,036 respondents | 13-25 Mental health | B                                      | 26% of young people in the UK with pre-existing mental health problems were not able to get psychological support during the lockdown. |

Note. A = Impact on children’s delivery of and access to healthcare; A1 = Reduction in use of primary care services and difficulties in accessing medication; A2 = Increased use of teledermatology; A3 = Delayed presentation to A&E departments and paediatric assessment units; A4 = Cancelled or suspended investigations and reduced surgical activity; A5 = Delays in diagnosis; B = Impact of innovative practice on children’s physical and mental health; C = Impact of service restrictions on children’s health; C1 = Increased disease severity; C2 = Increased mortality; C3 = Increased emergency and hospital admissions.
relevant papers included. Grey literature sources, including academic websites and websites of UK professional medical bodies (e.g. the Royal College of Paediatrics and Child Health), identified during the search period were also searched in order to ensure comprehensiveness. This manual search identified key grey literature sources and online reports which were not included in database searches.

A data-charting form was jointly developed by SL and JG to determine which variables to extract. The 2 authors independently charted the data, discussed the results and continuously updated the data-charting form in an iterative process.

Data were abstracted based on article aims and objectives, population (e.g. adult and child population, UK paediatric and international paediatric), health condition examined (e.g. asthma and mental health), healthcare type (e.g. unplanned/ emergency hospital admissions and primary care), and main findings for type of impact assessed.

A summary table demonstrating characteristics of the final articles is included in Table 1.

A thematic analysis was conducted on all selected papers to identify the key areas of impact on children during the pandemic. A coding protocol for the thematic analysis was developed by the 2 authors (SL and JG). The main findings relating to impact on children’s care, physical health and mental health were identified and coded. The codes were then grouped into the subthemes of impact type. Finally, the findings were iteratively summarised and grouped by SL and JG and discussed with IW and MS until consensus was reached [Table 1].

Results

The broad search in PubMed and PsycINFO identified 604 potentially relevant papers across both databases. The qualitative search in PubMed and PsycINFO identified 298 papers across both databases. After duplicates were removed the total number of articles was reduced to 689. Following title and abstract screening the number of selected articles went down to 96. A total of 14 papers were identified after full texts were examined. An additional 18 papers were identified through manual searches and reference lists. In total 32 papers were selected for the analysis [Figure 1].

Only 16 papers specifically focussed on the impact of changes in health care delivery on children in the UK, the others focussed on adult and child population in the UK or child population internationally. Papers directly referring to chronic conditions in children in the UK were limited to specific conditions, as follows: 3 papers focussed on asthma, 3 on diabetes, 3 on epilepsy, 2 on inflammatory bowel disease, 4 on mental health, 1 on neurodevelopment disorders and 1 on cancer. Fifteen papers did not focus on a specific chronic illness, and 9 of these papers explored the general impact of the pandemic on paediatric emergency care. The age range of children involved was from newborns to 18 years old. Most papers examined the impact of changes in healthcare delivery on children’s physical health except Serlachious et al (2020), Williams et al (2020) and Mansfield et al (2021) who discussed psychosocial challenges and impact on children with mental illness.3,8,9

Key Themes

Three themes were identified: (A) impact of health systems policy response on the delivery of and access to healthcare (B) impact of innovative practice on children’s physical and mental health (C) impact of service restrictions on children’s physical health.

Subthemes Emerged From Theme (A) and Theme (C)

Theme (A): ‘Impact on children’s delivery of and access to healthcare’ was grouped into 5 subthemes: (A1) reduction in use of primary care services and difficulties in accessing medication, (A2) increased use of telemedicine, (A3) delayed investigations and reduced surgical activity and (A4) cancelled or suspended investigations and reduced surgical activity and (A5) delays in diagnosis.

Theme (C): ‘Impact of service restrictions on children’s health’ was grouped into 3 subthemes: (C1) increased disease severity, (C2) increased mortality and (C3) increased emergency and hospital admissions.

The types of impact described are summarised below.

Impact on Delivery of and Access to Healthcare

A1 Reduction in use of primary care services and difficulties in accessing medication primary care contacts changed during the first part of the pandemic for children with acute physical and mental health conditions, such as depression and anxiety, eating disorders, self-harm behaviours and obsessive-compulsive disorder, cardiovascular and diabetic emergencies and asthma.3 GP contact levels between March and July 2020 were below the average of the previous 3 years, particularly for diabetic emergencies, depression and self-harm.3 There was an almost two-thirds reduction in unscheduled primary care visits in Scotland between 23rd March and 9th August 2020 compared with the same weeks in 2016–19.10 Some parents in London reported difficulty getting through to the receptionist at their GP surgery.11 Many young people with epilepsy and their caregivers reported barriers in acquiring a repeat prescription and contacting primary healthcare physicians or pharmacists.12,13

A2 Increased Use of Telemedicine

There was increased use of telemedicine within universal children’s services such as health visiting.2,14 A study on children with neurodevelopmental conditions found
restrictions to direct face-to-face clinician contacts, with many Community Child Health (CCH) services increasing their use of telemedicine markedly. Telephone consultation was the most commonly used method of remote contact, reported by 98% of healthcare practitioners.15

There was an increase in resources designed for children and young people (CYP) with Emotional, Behavioural, Neurodevelopmental and Intellectual disorders (EBNID) including Attention Deficit Hyperactivity Disorder (ADHD), Autism, Epilepsy and Cerebral palsy and their families including webinars, online videos, sleep tips and post-diagnosis support.15 Video consultations were also increasingly used for children with epilepsy.12,16

Telemedicine was also reported as the standard for treatment of children with inflammatory bowel disease during the pandemic and for the majority of children with diabetes.17-19

### A3 Delayed Presentation to A&E Departments and Paediatric Assessment Units

Since the start of the pandemic, there has been a significant decrease in under 16-year-olds presenting at and being admitted into A&E and paediatric emergency departments.4,10,14,20,21 Lynn et al. (2021) found that 32% of paediatricians working in emergency departments and assessment units reported delayed presentations with a range of between 14% in Wales to 47% in the Midlands.22 Two hospitals in Greater Manchester also reported a decline in paediatric emergency department (PED) attendances.20 In contrast, according to Roland et al. (2020), who examined hospital presentations with intermediate-risk and high-risk symptoms between 27th April and 15th May 2020, late presentation to emergency departments during this period was rare.23

Delayed presentations occurred most commonly in diabetes mellitus (DM) or diabetic ketoacidosis (DKA), along with sepsis and malignancy.22 In particular, a third of UK A&E paediatricians reported witnessing delayed presentations for new diagnoses of DM and DKA.2,3

### A4 Cancelled or Suspended Investigations and Reduced Surgical Activity

Between the 18th and 31st January 2021, paediatric and non-cancer elective surgery was occurring at less than a third of the rate of the previous year. In the most overwhelmed parts of the country, paediatric surgery fell to 12–20% of normal activity.24 These reductions significantly impacted the care of children with epilepsy. Between April – Sept 2020 surgical activity for epilepsy was limited or stopped entirely.12

Changes in the care of children with epilepsy during the pandemic includes decreased use of Electroencephalogram (EEG) and other cancelled investigations.12 Many young people and caregivers in the UK had investigations (EEG or MRI) cancelled by the hospital while some young people and caregivers cancelled investigations themselves.13 Video-EEG monitoring and other elective admissions were suspended.13

After recommendations by professional bodies and commissioners, multiple changes to cancer care have been established since the start of the pandemic, from the point of diagnosis (e.g. suspension of screening services) to treatment plans.25

There was a significant decrease in availability of lung function testing for children with chronic respiratory diseases; however, concerns have been partially overcome in some places with provision of home testing with either peak flow metres or portable spirometers.14

A study on children with neurodevelopmental conditions found restrictions to direct face-to-face clinician contacts and redeployment of staff from CCH services. Key clinical activities were limited, non-urgent new referrals were put on hold and CCH teams experienced significantly increased waiting lists.15

For children with inflammatory bowel disease there were difficulties in continuing day-case infusions, absence of face-to-face clinics and problems reviewing patients or performing routine blood or stool monitoring.17,26 Over 50% of CYP presenting with suspected IBD were diagnosed without the usual histological and endoscopic assessment because of the reduced use of endoscopy at over 90% of centres across the UK.17,26 According to 1 study only 13 of the 17 sites with available urgent endoscopy had performed the procedure, which translates to between 8 and 24 patients per site per week.26 Usually large paediatric gastroenterology centres would have 2–4 lists per week, with 4–6 patients per list.26 Reductions in endoscopy services were compounded by the redeployment of anaesthetic teams, while reduced space, extensive time for cleaning between cases and the need for PPE also affected the provision of these services.26

### A5 Delays in Diagnosis

Data collected from Salford in the UK found a large decrease in the rate of new diagnoses for circulatory system diseases, type 2 diabetes, malignant cancers and common mental health problems.9 Another UK-based study supported these results for cancer patients. Screening services were suspended and there was an 80% decrease in 2-week wait cancer referrals since March 2020 due to reduced diagnostic services including endoscopies, social distancing rules (including instructions for the public to present at GPs with urgent concerns only) and public health anxiety.25

Delayed diagnosis of paediatric DM and DKA have also been reported.2 This is concerning because DKA is a severe and life-threatening complication of diabetes and for treatment to start as soon as possible, early diagnosis of type 1 diabetes is necessary.19 Delays in diagnosis suggest a large backlog of patients may require attention by primary and secondary care.10
A prominent concern was about increased seizure severity in children with epilepsy due to difficulties accessing med-
icine, reduced access to health professionals and the addi-
tional stress, mood changes and sleep problems associated
with the pandemic.12,13 Additionally, the development-
tal trajectory of children with developmental and epileptic en-
cephalopathies is negatively affected by delayed or ineffect-
tive treatment.16 Some children will suffer irreparable
neurodevelopmental harm or even premature morbidity as a
consequence of delays in epilepsy surgery evaluations.16

The health of children with diabetes has also been sig-
ificantly affected by healthcare delivery changes during the
pandemic.18 A study on the views of diabetes nurses across
Europe found that an increase in acute hyperglycaemia was
reported by approximately 50% of respondents, with the UK
respondents rating physical impact on patients higher com-
pared to other European countries.18

Healthcare professionals expressed concerns about the
 provision of care for children with Inflammatory Bowel
Disease (IBD) during the pandemic, particularly the com-
 mencement of maintenance systemic immunosuppression
without endoscopic or histological diagnosis.26

The indirect impact of the pandemic was also significant
for cancer patients. For optimal outcomes, timely diagnosis
and treatment are vital but services were severely affected.
Oncologists were worried about the decreased referral rate for
suspected cancer in children.22,29

However, not all chronic illnesses have been affected in
the same way, with lockdown measures positively affecting
many children with asthma. This is notable considering that
the UK has one of the highest rates of asthma deaths in
Europe.30 Adherence to medical routines was improved in
many cases, as children spent more time at home with their
parents or caregivers.10,30 Reductions in air and road traffic,
decreased interaction between children, restricted travel,
shielding and social distancing may have also contributed. An
international study on paediatric asthma reached the same
conclusions.27

**C2 Increased mortality.** Delayed presentation of children
to A&E departments may have resulted in avoidable child
mortality.4,29 Data from Salford showed delayed or missed
diagnosis of common mental health problems, cardiovas-
cular and cerebrovascular disease, type 2 diabetes and cancer.9
A further study demonstrated that a decrease in
primary care visits, A&E attendances and unplanned hospital
admissions were not associated with increased mortality rates
in ages 0–14 years.9 Moreover, despite the increase in PICU
admissions, there were no significant changes in paediatri-
c morbidity for the period between 29th March and 9th August
across any age group examined.10

A study on the impact of delays in cancer diagnosis in
adults and children estimated that between 3291 and 3621

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**Impact of Innovative Practice on Children’s Mental and Physical Health**

Digital healthcare increased access for children with mental
health difficulties. 26% of young people in the UK with pre-
existing mental health problems were unable to access
psychological support during the lockdown; however, a large
number reported receiving treatment on the phone or through
video calls.27 Primary and secondary care services provided
both emergency and routine care to people with diabetes on
the phone or via video consultations, including mental health
support.28 Although it is not yet clear what impact the change
to telehealth will have on diabetes outcomes, the majority of
respondents to a pre-pandemic survey found virtual appoint-
ments useful.18 In contrast, the use of telehealth for people with cancer suggests a greater proportion of missed
diagnoses.25

Use of telemedicine also increased for children with
epilepsy.12 Virtual diagnosis without the use of EEG could
have decreased accuracy, and misdiagnosis could have
adverse outcomes for children unnecessarily exposed to the
side effects of treatment.16 Additionally, having difficult
health-related conversations virtually may negatively im-
pact patient mental health.16 The majority of respondents in
one study considered telehealth to be as effective as in-
person consultations.12 However, some young people with
epilepsy and their caregivers stated that they were less
satisfied with telehealth.12 Many respondents to another
survey felt that the care received through telehealth with the
GP was inadequate, with language barriers cited as a fac-
tor.11 In-person appointments were preferable for patients
with additional needs, such as those with autism or hearing
loss.13

Reliance on telehealth may have resulted in missed di-
gnoses for common mental health problems, cardiovas-
cular and cerebrovascular disease, type 2 diabetes and cancer.9
Delays in diagnosis for these conditions have been associated
with higher rates of mortality, with particular concern for
patients with depression.9

**Impact of Service Restrictions on Children’s Physical Health**

**C1 Increased disease severity.** Decreases in primary care visits,
A&E attendances and unplanned hospital admissions did not
result in greater disease severity upon presentation to PICU in
Scotland during the lockdown.16 However, other research
suggests that reduced access to healthcare and disruptions to
planned outpatient visits and operations may have led to
increased child morbidity.2,4 This is a particular concern for
children who are also missing the developmental support and
access to therapies from school, such as children with cerebral
palsy or musculoskeletal problems.14 Many health profes-
sionals were concerned about the wellbeing of the children
they were not seeing.3
avoidable deaths will have occurred from 5 cancer types in the 5 years after diagnosis compared with the pre-pandemic period. An additional 59,204–63,229 years of life lost will be attributable to delays in cancer diagnosis alone as a result of the first COVID-19 lockdown in the UK.25

C3 Increased emergency and hospital admissions. Encouragingly, one study found that among the children with delayed presentations to A&E departments, only 11.8% were admitted to hospital, suggesting limited effect on outcomes.23 Contrastingly, Williams et al. (2021) found an increase in symptom severity upon presentation at A&E during the pandemic in Scotland.10 Paediatric ED admissions in Oxfordshire were significantly reduced compared with the previous 5 years across all age groups.31 Yet despite a decrease in admissions, a greater proportion of children admitted received more than 10 diagnoses, suggesting an increase in children with severe or complex disease.31

Fewer children and young people presented at emergency departments with severe asthma during the pandemic.36,31 A study on both UK adults and children showed that in the week after lockdown (23rd–29th March) attendance at A&E was down 25% on the previous week.32 There was a 77% decrease in admissions to PICU for disorders of the respiratory system and a decrease in admissions for the neurological system according to primary and secondary care providers in Scotland.10

In contrast, high numbers of patients were requiring emergency care due to epilepsy or related injuries during the pandemic.13 There were more urgent admissions for patients with malignancies, which could be explained by reductions in face-to-face primary care contacts, and/or changes to tertiary oncology services with the restrictions to elective admissions.31

Discussion

The results of this review indicate that delivery of, and access to, healthcare for children with chronic illness was significantly affected during the pandemic. A number of factors led to these changes. These include lockdown measures, the shielding of people with certain health conditions and the recommendations by professional bodies and commissioners prioritising the response to the pandemic.2,3,8,33 Similar challenges in the provision of healthcare for children with chronic illness including epilepsy, asthma and diabetes were also reported internationally including in US, Asia and Europe.16,18,19,34 Due to the restrictive measures and increased health anxiety, the health-seeking behaviour of UK caregivers changed, with many families deciding to stay away from hospital, to delay presentation at a healthcare setting or to miss their routine health checks.11,12,35 Decreases in access to healthcare were seen across healthcare settings including primary care hospital and A&E.3,10,22,29,36

Due to the changes in child healthcare provision, significant unmet need was identified which could result in increases in morbidity and mortality for children with various physical and mental health conditions.2,3 Social distancing measures meant that vulnerable children missed regular contact with education, health and social care professionals. It is estimated that many children may have been experiencing maltreatment, neglect or domestic violence unknown to professionals.2,20 Parents’ reluctance to seek healthcare during the pandemic indicates that many children remained at home with serious pathologies or illnesses.2

One of the most prominent changes in the delivery of healthcare across different health conditions was the use of telehealth.19 Although this reduced the risk of Covid-19 infection, views on its efficacy are mixed. Inconsistent efficacy rates are expected to lead to a large backlog of patients who require care for undiagnosed conditions.9

The need for children to access psychological support has increased during the pandemic. This is particularly concerning for children with chronic health conditions as they are more likely to experience psychosocial difficulties. Diabetes patients are two to three times more likely to have depression and young people with epilepsy are at an increased risk of mental health and behavioural problems.12,19 Due to lockdown measures, CYP’s needs for psychological support were in many cases unmet, irrespective of condition-type. Moreover, school closures removed another potential source of psychological support.14

Unmet mental health needs can impair the health and wellbeing of children with chronic illness in many ways.13 For instance, the psychological distress experienced by people with epilepsy during the pandemic may have caused an increase in seizures and poor mental health can have a negative impact on diabetes control and blood glucose levels.12,13,19

This study has shown that health systems policy responses to the pandemic have significantly affected the care and health of children with chronic illness in the UK, providing evidence pointing to areas that need further research. However, there are some methodological considerations and limitations of our study that 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. The health conditions mainly discussed were asthma, diabetes, epilepsy, cancer and inflammatory bowel diseases and some neurodevelopmental and mental health conditions. Although there seems to be some information on projected health outcomes for children with chronic illness, and some comparisons with international studies and the adult population are also drawn, there is scarce evidence thus far on how changes in service provision affected children with chronic illness in the UK.
Conclusion

This review has demonstrated that health systems policy responses to the pandemic had wide-reaching impacts on the delivery of, and access to, child healthcare in the UK. However, the specific assessment of the impact of service restrictions and innovative practice on the health and well-being of children with chronic illness in the UK is limited. Important implications about evidence-based policy can, however, be drawn from this research. The lack of sufficient evidence suggests 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 fairly considered in evaluating health systems policy responses to the pandemic. The paucity of research into child health does not only apply to the subject of Covid-19 but it is a general problem suggesting the potential of bias in the development of information technology and healthcare planning,37 and can therefore have wide-reaching policy implications. Assessing whether and how children’s needs were met during the pandemic is an important step to designing resilient and effective health systems and informing policy response to future emergencies. Future research is required to fulfil knowledge gaps regarding in access to effective diagnostic and treatment investigations and their impact on a range of paediatric patients during the pandemic. This scoping review is the first phase of work investigating the impact of the health system changes on children with chronic illness in order to inform the development of an ethical framework for how the needs of those children should be fairly considered in the pandemic context.

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Supplemental material

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References

1. The Royal College of Paediatrics and Child Health. In: The Case for Investing in Integrated Child Health Services for the Acutely Unwell Child and Long Term Conditions. London, UK: RCPCH; 2019. https://www.rcpch.ac.uk/resources/case-investing-integrated-child-health-services-acutely-unwell-child-long-term-conditions. Accessed September 22, 2021.
2. Heffron C, Taylor C, Bennett D, et al. Priorities for the child public health response to the COVID-19 pandemic recovery in England. Arch Dis Child. 2021;106:533-538.
3. Mansfield K, Mathur R, Tazare J, et al. Indirect acute effects of the COVID-19 pandemic on physical and mental health in the UK: a population-based study. Lancet Digital Health. 2021;3(4):e217-e230.
4. The Royal College of Paediatrics and Child Health. Impact of Covid-19 on Child Health Services. London, UK: RCPCH; 2020. Impact -of-COVID-19-child-health-services-web.pdf.pdf (rcpch.ac.uk. Accessed August 20, 2021.
5. The Academy of Medical Sciences COVID-19. Preparing for the Future Looking Ahead to Winter 2021/22 and beyond; 2021. https://acmedsci.ac.uk/file-download/4747802. Accessed August 20, 2021.
6. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol. 2018;18(1):143.
7. Tricco AC, Lillie E, Zarin W. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):476-473.
8. Serlachius A, Badawy SM, Thabrew H. Psychosocial challenges and opportunities for youth with chronic health conditions during the COVID-19 pandemic. JMIR Pediatr Parent. 2020;3(2):e23057.
9. Williams R, Jenkins DA, Ashcroft DM, et al. Diagnosis of physical and mental health conditions in primary care during the COVID-19 pandemic: a retrospective cohort study. Lancet Public Health. 2020;5(10):e543-e550.
10. Williams T, Macrae C, Swann OV, et al. Indirect effects of the COVID-19 pandemic on paediatric healthcare use and severe disease: a retrospective national cohort study. Arch Dis Child. 2021;106:911-917.
11. Watson G, Pickard L, Williams B, et al. ‘Do I, don’t I?’ A qualitative study addressing parental perceptions about seeking healthcare during the COVID-19 pandemic. Arch Dis Child. 2021;106:1118-1124.
12. Reilly C, Muggeridge A, Cross JH. The perceived impact of COVID-19 and associated restrictions on young people with epilepsy in the UK: young people and caregiver survey. Seizure. 2021;85:111-114.
13. Thorpe J, Ashby S, Hallab A, et al. Evaluating risk to people with epilepsy during the COVID-19 pandemic: preliminary findings from the COV-E study. Epilepsy Behav. 2021;115:107658.

14. Ashikkali L, Carroll W, Johnson C. The indirect impact of COVID-19 on child health. J Paediatr Child Health. 2020;30:430-437.

15. Ogundele M, Ayyash H. Effect of covid-19 lockdown on the configuration and implementation of services for children and young people with neurodevelopmental disorders in the UK. 2021;5:A77.

16. Wirrell E, Grinspan Z, Knupp K, et al. Care delivery for children with epilepsy during the COVID-19 pandemic: an international survey of clinicians. J Child Neurol. 2020;35(13):924-933.

17. Ashton JJ, Batra A, Coelho TAF, et al. Challenges in chronic paediatric disease during the COVID-19 pandemic: diagnosis and management of inflammatory bowel disease in children. Arch Dis Child. 2020;105:706.

18. Forde R, Arente L, Ausili D, et al. The impact of the COVID-19 pandemic on people with diabetes and diabetes services: a pan-European survey of diabetes specialist nurses undertaken by the Foundation of European Nurses in Diabetes survey consortium. Diabet Med. 2021;38(5):e14498.

19. Elbarbary NS, Jeronimo dos Santos T, de Beaufort C, et al. COVID-19 outbreak and pediatric diabetes: perceptions of health care professionals worldwide. Pediatr Diabetes. 2020;21(7):1083-1092.

20. Isba R, Edge R, Jenner R, et al. Where have all the children gone? Decreases in paediatric emergency department attendances at the start of the COVID-19 pandemic of 2020. Arch Dis Child. 2020;105:704.

21. Mulholland R, Wood R, Stagg HR, et al. Impact of COVID-19 on accident and emergency attendances and emergency and planned hospital admissions in Scotland; an interrupted time-series analysis. J R Soc Med. 2020;113(11):444-453.

22. Lynn RM, Avis JL, Lenton S, Ladhani SN. Delayed access to care and late presentations in children during the COVID-19 pandemic: a snapshot survey of 4075 paediatric patients during the COVID-19 era. BMJ. 2020;369:m2624.

23. Cameron C, Hauari H, Hollingworth K, et al.. The First 500: The impact of Covid-19 on Families, children Aged 0-4 and Pregnant Women in Tower Hamlets. London, UK: University College London Institute of Education; 2021. Interimbriefingreportfinal9December2020pdf(uclacuk). Accessed August 1, 2021.

24. Kelly E, Firth Z. How is COVID-19 changing the Use of Emergency care? The Health Foundation; 2020. https://www.health.org.uk/news-and-comment/charts-and-infographics/how-is-covid-19-changing-the-use-of-emergency-care-by-region. Accessed August 1, 2021.

25. Maringe C, Spicer J, Morris M, et al. The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study. Lancet Oncol. 2020;21(8):1023-1034.

26. Ashton J, Kammermeier J, Spray C, et al. Impact of COVID-19 on diagnosis and management of paediatric inflammatory bowel disease during lockdown: a UK nationwide study. Arch Dis Child. 2020;105:1186-1191.

27. Young Minds. Coronavirus: impact on Young People with Mental health Needs; 2020. https://youngminds.org.uk/about-us/reports/coronavirus-impact-on-young-people-with-mental-health-needs/. Accessed June 01, 2021.

28. Hartmann-Boyce J, Morris E, Goyder C, et al. Diabetes and COVID-19: risks, management, and learnings from other national disasters. Diabetes Care. 2020;43:1695-1703.

29. Wise J. Covid-19: Delays in attending emergency departments may have contributed to deaths of nine children. BMJ. 2020;369:m2604.

30. Creese H, Taylor-Robinson D, Saglani S, Saxena S, et al. Primary care of children and young people with asthma during the COVID-19 era. Br J Gen Pract. 2020;528-529.

31. Charlesworth JEG, Bold R, Pal R. Using ICD-10 diagnostic codes to identify ‘missing’ paediatric patients during nationwide COVID-19 lockdown in Oxfordshire, UK. Eur J Pediatr. 2021;3343-3357.

32. Thornton J. Covid-19: A&E visits in England fall by 25% in week after lockdown. BMJ. 2020;369:m1401.

33. Jia Y, Bao J, Yi M, et al. Impact of the COVID-19 pandemic on asthma control among children: a qualitative study from caregivers’ perspectives and experiences. BMJ Open. 2021;11(5):e046525.

34. Papadopoulos N, Custovic A, Deschilde A, et al. Impact of COVID-19 on pediatric asthma: practice adjustments and disease burden. J Allergy Clin Immunol. 2020;8(8):2592-2599.

35. Hussein I, Xiaoxuan L, Nevine Z. Health data poverty: an assailable barrier to equitable digital healthcare. The Lancet Digital Health. 2020;3(4):e260-e265.