Examining Patterns of Urgent and Emergency Care Service Use by Children and Young People

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Contents

List of Abbreviations

A&E	Accident and Emergency
AIC	Akaike Information Criterion
BMA	British Medical Association
BMI	Body Mass Index
C&YP	Children & Young People
CCDF	Complementary Cumulative Density Function
CDS	Commissioning Data Sets
CI	Confidence Interval
CURE	Centre for Urgent and Emergency Care Research
ECDS	Emergency Care Data Set
ED	Emergency Department
EHR	Electronic Health Records
ENT	Ear, Nose and Throat
ER	Emergency Room
GLM	Generalised Linear Model
GP	General Practitioner
HRA	Health Research Authority
ICD-10	International Classification of Diseases 10^{th} Revision
IMD	Index of Multiple Deprivation
IRR	Incidence Rate Ratio
NA	Not Applicable
NHS	National Health Service
NIH	National Institute of Health
NR	Not Reported

OR	Odds Ratio
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
REF	Reference Category
SCHARR	Sheffield Centre for Health and Related Research
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
UEC	Urgent & Emergency Care
UK	United Kingdom
USA	United States of America
UTC	Urgent Treatment Centre
VM	Virtual Machine
VPN	Virtual Private Network
WHO	World Health Organisation

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Abstract

Background

Demand for urgent and emergency care services such as emergency departments (EDs) is rising in the UK. Concerns have been raised regarding the consequences of increased strain on these services for specific patient groups such as children and young people. For parents and caregivers, deciding the most appropriate healthcare service for their child can be challenging, as children and young people are often extremely vulnerable with specialised healthcare needs. To assist parents and caregivers with this decision making process, the telephone triage service NHS 111 is tasked with providing callers with healthcare advice and recommending relevant healthcare services. However, there is evidence to suggest that the telephone triage service is leading to a number of avoidable ED attendances, further increasing the strain on other urgent and emergency care services. Although the use of pre-hospital services such as NHS 111 is a pivotal component of a child's urgent and emergency care journey, another important consideration is those who frequently use urgent and emergency care services such as EDs. High frequency ED attenders often represent a small proportion of attenders but make a relatively large number of attendances. The reasons behind why these children and young people frequently attend EDs consists of confounding factors such as parental anxieties and reduced access to other healthcare services. Examining these factors in detail can highlight interventions aimed at improving the management of high frequency ED attenders within the ED, but may also improve the safety of these individuals outside the urgent and emergency care system. The overarching aim of this PhD is to analyse routinely collected patient data to provide insights into the use of urgent and emergency care services such as EDs by children and young people. This is achieved by analysing

parental/caregiver, socioeconomic and medical factors associated with a child's urgent and emergency care journey.

Overarching Aim

To use routinely collected patient data to provide insights into the use of EDs and other urgent and emergency care services by children and young people.

Primary Research Objectives

1. To understand more about the relationship between NHS 111 pathways and ED outcomes for children and young people.
2. To determine the statistical distribution underpinning the number of ED attendances children and young people make, and examine methods of assessing factors associated with high frequency ED attendance.
3. To explore factors associated with high frequency ED attendance by children and young people.
4. To measure ED attendance patterns and examine heterogeneity in reasons for attendance in children and young people.

Methods

This quantitative PhD analysed routinely collected patient data collected within the Yorkshire and Humber region of the UK, stored within the CUREd research database. Two systematic reviews were conducted to explore what had been previously published on the use of telephone triage services prior to an ED attendance in children and young people, and high

frequency ED attendance by children and young people respectively. Standard approaches for systematic reviews were adopted and reported against PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines. A variety of statistical methods were implemented to address the above research objectives. These include a number of statistical models such as logistic, zero truncated poisson, quantile and mixed effects regression models, and statistical tests such as likelihood ratio and chi-squared tests. Other statistical approaches include the use of a Herfindahl index to measure the heterogeneity of reasons for ED attendances and the implementation of an expectation-maximisation algorithm to model the time taken for an individual to attend ED after contacting NHS 111.

Results

The telephone triage systematic review concluded that these services may be leading to a number of inappropriate ED attendances by children and young people (especially when the call did not involve input from a clinical expert). It also highlighted a gap in the evidence exploring urgent and emergency care pathways made by children and young people following contact with NHS 111. The high frequency ED attender systematic review found that studies often use a numeric threshold (ranging from 2-6 attendances made in a year) for defining high frequency ED attenders. This highlighted the need for a novel statistical approach to assess factors associated with high frequency ED attendance without needing to categorise high frequency ED attenders in this way. This systematic review also revealed a gap in the evidence for exploring high frequency ED attendance by children and young people over multiple years in addition to the heterogeneity of reasons for attending. The first study conducted in this PhD analysed 348,401 calls made to NHS 111 regarding children and young people, and found that 45,746 (13.3%) led to an ED attendance within 24 hours. The

time taken for individuals to attend ED following contact with NHS 111 could be categorised into two relatively distinct waves, with most attending soon after the call and a proportion attending later. Of those attending an ED after being told to do so by NHS 111, over a quarter resulted in a low acuity attendance. Young age (<1) was found to be associated with low acuity ED attendances following contact with NHS 111, irrespective of the disposition provided during calls. The second study conducted in this PhD analysed the yearly ED attendances made by children and young people and provided evidence to suggest the underlying distribution follows a heavy tail distribution such as the discrete power law or lognormal. This study proposes the use of a zero truncated or one inflated zero truncated poisson model in combination with a quantile count regression model to analyse this in children and young people. As this distribution was found to be heavy-tailed in nature this provided evidence to suggest ED use by children and young people represents characteristics of a complex system. The third study conducted in this PhD found that high frequency ED attenders were more likely to be admitted to hospital after attending an ED, in comparison to occasional users. When considering factors associated with ED attendance rates in ED users, younger age groups and greater levels of deprivation were found to be associated with higher rates of attendance. This association was amplified in those attending the ED most often. Ethnicity was also found to be associated with ED attendance rates. The final study conducted during this PhD analysed ED attendances made by children and young people over a two-year period. Although a relatively small proportion of individuals were defined as high frequency ED attenders in their first observation year (9,700, 13.6%), over half of these individuals made at least one attendance in their second observation year (5,345, 55.1%). The analysis of reasons for attendance in individuals (making 7-13 ED attendances in the observation period) found those aged 8-12 were more likely to make injury related attendances and less likely to make illness related attendances. Conversely, those under the

age of 1 were less likely to make injury related attendances and more likely to make illness related attendances. There was less heterogeneity in the reasons for attendance in those aged 8-12 in comparison to those under the age of 1.

Conclusion

The factors associated with the use of urgent and emergency care services by children and young people represent a complex interplay of medical, socioeconomic and parental/caregiver decision making considerations. This PhD has demonstrated how large quantities of routine patient data can be used to provide insights into the use of urgent and emergency care services by children and young people. However, when using routine patient data it can be challenging to distinguish between high frequency ED users making clinically appropriate ED attendances for reasons such as chronic conditions, and those making less clinically appropriate ED attendances due to factors such as parental anxiety and reduced access to primary care services. Although targeted interventions should be implemented to assist parents and caregivers when making health-related decisions for their child, as the urgent and emergency care system comprises a number of interacting components, these interventions must also consider the wider healthcare system and beyond.

Dissemination

Publications

Published

Kumar, A., Kerryn, H., Simpson, R., Johnson, G., Burton, C. 2023. Use of Emergency Departments by Children & Young People Following Telephone Triage: A Large Database Study, *Emergency Medicine Journal*.

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Kumar, A., Kerryn, H., Simpson, R., Johnson, G., Burton, C. 2023. Examining Statistical Distributions and Models for Analysis of Emergency Department Attendance Rates by Children & Young People.

Kumar, A., Kerryn, H., Simpson, R., Johnson, G., Burton, C. 2023. Exploring Factors Associated with High Frequency Emergency Department Attendance by Children & Young People: A Retrospective Cohort Study.

Kumar, A., Kerryn, H., Simpson, R., Johnson, G., Burton, C. 2023. Examining High Frequency Emergency Department Use and Reasons for Attendance by Children & Young People: A Retrospective Cohort Study.

Conference Presentations

Kumar, A., Kerryn, H., Simpson, R., Johnson, G., Burton, C. 2023. Exploring Emergency Department Use in Children & Young People Following Contact with The Telephone Triage Service NHS 111, ScHARR Pgr Conference 2023.

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1 Introduction

1.1 Thesis Structure and Layout

This thesis is presented in the form of a publication format thesis, which comprises a number of publication-style chapters suitable for submission to a peer-reviewed journal, and appear alongside traditional thesis chapters. Each of the publication-style chapters have either been submitted to a peer-reviewed journal or are planned for submission. Throughout this thesis, chapters are supported by a commentary that links the publication-style chapters with the traditional thesis chapters.

This thesis begins with a background chapter outlining urgent and emergency care (UEC) within the UK, with specific emphasis placed on understanding demand for these services by children and young people (C&YP). This chapter ends by describing how the information presented in the background section (in combination with advice provided by medical practitioners and researchers) highlighted two main areas of interest. These were concerning the use of telephone triage services prior to an ED attendance by C&YP, and high frequency ED use by C&YP. Chapters 3 and 4 present two systematic reviews produced in this PhD to identify existing evidence and knowledge gaps when addressing the two above research areas. These chapters outline evidence gaps and are used to formulate the following 4 PhD primary research objectives:

- To understand more about the relationship between NHS 111 pathways and ED outcomes for C&YP.
- To determine the statistical distribution underpinning the number of ED attendances C&YP make, and examine methods of assessing factors associated with high frequency ED attendance.
- To explore factors associated with high frequency ED attendance by C&YP.

- To measure ED attendance patterns and examine heterogeneity in reasons for attendance in C&YP.

Chapter 5 provides details of the methods used to address each of the research objectives. This methodology section also describes the use of healthcare data for quantitative research and outlines how and why large quantities of electronic health records were analysed in this PhD. Chapters 6, 7, 8 and 9 present the main methods and findings of the PhD research undertaken to address the above research objectives. These chapters are presented in a manuscript form and include the motivation behind the study, a background of the problem, the methods used to address the research objective, a results section and a discussion section. The final chapter of this thesis provides an overview of the work conducted in this PhD and critically summarises how these results affect practice and policy. Chapter 6 has been submitted as a publication to the Emergency Medicine Journal (EMJ), with chapters 7, 8 and 9 in preparation for submission.

This PhD produced novel contributions to knowledge in the field of UEC for C&YP. The main features of this quantitative PhD were:

- The implementation of two systematic literature reviews exploring evidence published in relation to the use of telephone triage services prior to an ED attendance in C&YP, and high frequency ED use in C&YP. These reviews enabled me to identify avenues of research to be conducted in the analysis phase of the PhD.

- The study of a large database of routine patient data to explore calls made to the telephone triage service NHS 111 and subsequent UEC pathways in C&YP. This included the analysis of two large linked datasets (ED attendances and NHS 111 calls) providing novel insights into the use of UEC services by C&YP.

- The statistical analysis of the yearly ED attendances made by C&YP to recommend the use of statistical models to analyse factors associated with ED attendance rates in C&YP. These models were used to provide insights into the use of EDs by these individuals.
- The study of a large database of routine patient data to explore high frequency ED attendance in C&YP over a 2 year period, with specific emphasis placed on the reasons for attending.

1.2 Declarations and Author Contributions

In accordance with the university of Sheffield's policy for publication-format theses, I can confirm that this thesis is my own work. Although supervisors assisted with the design and conduct of the reported research (and are included as authors in papers), the work produced was largely my own as primary author. I was the study lead for all the studies and produced the manuscripts outlined in this thesis. All supervisors provided advice on editorial changes for the study manuscripts. Chris Burton is the lead supervisor for all the studies and contributed to the development of the research question and its overall design. Kerryn Husk also assisted with the conception and design of studies. Rebecca Simpson specifically contributed by reviewing the statistical analyses used in studies. Chris Burton and I contributed to the acquisition of the data used in this PhD from the CUREd database. I was responsible for cleaning, validating and analysing the data. Graham Johnson informed the clinical importance of the studies conducted in the PhD.

2 Background

2.1 Chapter Outline

This chapter begins by providing an introduction to urgent and emergency care (UEC) services in the UK. Examples of both pre-hospital (including NHS 111), and patient facing UEC services (such as EDs) are given and described within the context of the NHS. This chapter then explains how demand for UEC services has increased in recent years and outlines government/NHS interventions aimed to combat this. Specific emphasis is placed on the use of UEC services by children and young people (C&YP), with the phenomenon of high frequency ED attendance introduced in this demographic. This chapter then describes medical and non-medical factors associated with ED use by C&YP, and concludes by summarising how the chapter helped focus the research conducted in this PhD through the formulation of two sets of systematic review questions.

2.2 Introduction to Urgent and Emergency Care within the UK

UEC services are a pivotal component of healthcare systems in the UK and abroad, with a number of services available directly to the patient.[1] In the UK, UEC services include emergency departments (EDs), urgent treatment centres (UTCs, such as walk-in centres or minor injury units), NHS out-of-hours services (including NHS 111) and emergency ambulance services.[2] Although primary care providers are designed to be the first point of contact for patients requiring different forms of non-urgent treatment, services such as general practitioners (GPs), pharmacists, dentists and opticians also play a role in the provision of UEC.[2] This is because primary care providers may be required to carry out UEC treatment, and direct patients to UEC services.[3]

2.3 Categories of Urgent and Emergency Care

In the UK, face-to-face UEC services are divided into four categories, each providing different levels of care.[4] Type 1 UEC services are defined as major, consultant-led emergency departments (EDs, also known as Accident and Emergency, A&E) with full resuscitation facilities operating 24/7. Type 2 UEC services are defined as consultant-led single specialty services (such as an ophthalmology ED). Type 3 UEC services are other EDs, minor injuries units or urgent care centres treating minor injuries or illnesses, and can be doctor or nurse-led (accessible without an appointment). Finally, Type 4 UEC services are defined specifically as NHS walk-in-centres for acute non-emergency care.[1] UEC may also be provided by aligned services including ambulance services, GPs and the medical telephone triage service NHS 111.[5]

2.4 Other Sources of Urgent and Emergency Care

2.4.1 Ambulance Services

999 is an official emergency telephone number in several countries and enables the caller to contact emergency services for urgent assistance. In the UK, the NHS advise individuals to call ambulance services in the case of a medical emergency, which is defined as a situation where someone is seriously ill or injured and their life is at risk.[2] When 999 is called, a trained call handler will ask a number of questions to promptly ascertain which course of action should be taken (with the assistance of a decision-making software categorising calls into time-critical categories).[6] If the call handler determines the call is regarding a life-threatening emergency, an ambulance, rapid response vehicle and/or a community first responder (or combination of response units) will be dispatched, and further instructions

provided to the caller.[2] On arrival, paramedics then treat the patient and ascertain if further treatment in UEC services such as the ED is required.

2.4.2 General Practice Surgeries

GPs are regularly used as an initial point of contact for individuals requiring treatment for a variety of medical conditions, and can also direct patients to other services for specialist treatment.[7] GPs play an important role in providing safe and effective urgent care to a number of patients, as individuals may attend GP surgeries with urgent and life-threatening conditions such as asthma attacks, anaphylaxis and suspected heart attacks or strokes.[8] In these cases GPs will provide life-saving urgent treatment and make swift decisions to determine the urgent care pathway the patient needs to take. In addition to the direct relationship between GPs and the provision of UEC, research has suggested that indirect factors such as the availability of GP appointments are associated with a patient's use of UEC services, with an estimated 5.77 million ED attendances occurring in England (2012-2013) after a patient was unable to obtain a GP appointment.[9]

2.4.3 NHS 111

NHS 111 is a free-to-call telephone triage service designed to make it quicker and easier for patients concerned about their physical and mental health to obtain medical advice or treatment.[10] NHS 111 is operational twenty-four hours a day, seven days a week and also consists of a website (111.NHS.uk).[2] In 2007 the Department of Health published a report named "Our NHS, Our Future" which identified potential issues within the NHS and suggested ways in which services could be improved.[11] This report recommended the introduction of a single three-digit number in addition to 999 to improve and simplify public

access to urgent healthcare. The intention behind the proposed service derived from feedback suggesting that patients often found it "confusing to know which NHS service to access for routine or urgent care".[11] This report also suggested that the existence of a single non-emergency medical helpline could reduce the strain on UEC services within the NHS by ensuring the correct treatment pathways are provided to the patient. In 2017/2018, the NHS extended the service to provide non-emergency medical advice online as well as over the phone. NHS 111 online can be accessed via the NHS website or NHS app, and prompts users to answer questions regarding their symptoms to assist the healthcare triage process. Similarly with NHS 111 calls, patients can be directed to a variety of services when using NHS 111 online, with early research conducted using NHS Digital data reporting that 48% of all NHS 111 online triages directed users to contact primary care services, 24.7% of triages instructed users to ring 999 or attend an ED, and 13% of triages provided self-care advice.[12] Further to NHS 111 as a service attempting to reduce strain on UEC services, the NHS have now also implemented an urgent treatment centre (UTC) model (with appointments booked through contact with NHS 111) to ensure patients have a consistent offer for out-of-hospital urgent care.[13]

2.5 Demand for Urgent and Emergency Care Services

Although a number of UEC routes are directly available to patients, in recent years UEC services have been under increasing pressure, with the number of patients attending UK EDs increasing by 40% from the years 2006 to 2020.[14] Unsustainable rises in ED attendances may contribute to emergency healthcare implications such as ED overcrowding, which is becoming a growing problem within the UK.[15] ED overcrowding can cause delays in the emergency care provided to patients which can have a detrimental effect on patient outcomes.[16] In addition to EDs, other UEC services are also seeing a large increase in

demand, with the volume of emergency calls to ambulance dispatch centres in England doubling from 4.72 million in 2001/02, to 9 million in 2014/15.[17] During the Covid-19 pandemic, Wales saw a significant increase in demand for ambulance services with then minister for Health and Social Services Vaughan Gething stating "The ambulance service faced significant pressure, with average daily red calls increasing to the highest point on record and exceeding 100 for the first time".[18] Further to specialist UEC services such as EDs and ambulance services, primary care services such as GPs have seen increases in demand in recent years, with the British Medical Association (BMA) recently stating that GP surgeries across the country are experiencing significant and growing strain with rising demand.[19] As primary care services are often an initial point of contact for parents and caregivers, research has suggested that reduced access to these services can result in increased use of UEC services by C&YP. [20]

2.6 Use of Urgent and Emergency Care Services by Children and Young People

Although previous studies have explored pressures on UEC services, the main focus tended to be on predominantly older individuals and adults.[21] This is justified by evidence suggesting that adults are more likely to have longer lengths of stays within EDs and are often more acutely ill than younger patients.[22] However as short-stay emergency admissions (<1 day) have been increasing for C&YP, studies evaluating the use of UEC services in this demographic are equally important.[23] Furthermore, even when pre-hospital non-emergency medical advice had been provided (via telephone triage services such as NHS 111), studies have suggested that young children are still likely to attend EDs when more appropriate services were available.[24] To this end, a nationwide study based in the UK suggested that children aged 0-4 were more likely to result in an avoidable ED attendance after contacting NHS 111 than adults.[24] Studies have also suggested that C&YP defined as high frequency ED

attenders often make a large proportion of ED attendances and therefore contribute to increased demand for UEC services.[25]

2.7 Factors Associated with ED Use by Children & Young People

2.7.1 Parental Styles and Decision Making

One of the most important factors affecting the demand for UEC services by C&YP are parental attitudes towards such services.[26] Published literature outlines the importance of family and parental intervention when healthcare decisions are being made for their child.[27] One study concluded that parental factors such as: the parents' willingness to tolerate somatic symptoms in the child, health anxiety, council house tenancy and the parents' own attendance history were associated with children responsible for the most GP consultations.[28] Although these socioeconomic factors require further exploration for UEC services, council house tenancy may be associated with the reduced availability and quality of other healthcare services in the local area, thus increasing demand for GPs. As parental health anxiety and their own attendance history are predictors of high frequency use of GPs - this could imply that healthcare providers may need to explore ways in which parental health-related decision-making can be assisted. In addition to primary care service use, a systematic review exploring parental reasons behind ED use in C&YP found that the perceived urgency of the medical episode played a large part when choosing to take their child to an ED.[29]

2.7.2 Medical Reasons and Chronic Conditions Associated with ED Use

A variety of medical factors exist when considering UEC service use by C&YP. Since C&YP have differing emergency healthcare needs in comparison to adult patients, specialist paediatric EDs can provide more specialised treatment. One of the leading reasons why

paediatric emergency healthcare needs differ greatly from adults, is the physiological discrepancy between the two demographics.[30] For example, as children have less fluid in their bodies in comparison to adults, fluid loss from emergency situations (such as dehydration or excessive bleeding) can have a greater detrimental effect on children.[31] In addition to this, as viral infections are more common in C&YP (as they have had less time to build up prior immunity and are generally exposed to a variety of different viruses), they are more likely to be infected than adults.[31] Since respiratory viruses are more likely to cause serious illness in infants, these individuals often attend EDs to treat these problems.[32] C&YP with chronic conditions or disabilities are likely to display higher ED use due to their complex health needs. In particular, one study exploring ED use in USA found that C&YP with the highest rates of ED attendance were living with chronic conditions such as sickle cell anemia, epilepsy and asthma.[33] Admission rates to the hospital were found to be significantly higher for C&YP living with chronic conditions, as one study suggests that almost 40% of these C&YP seen in the ED were subsequently admitted to hospital.[34] Further to this, the study also suggests that fever, respiratory distress, headaches and seizures were overrepresented in chronically ill children. Due to the high UEC utilisation displayed by C&YP living with chronic conditions, one study estimates that an additional $1,377-$9,059 was spent on annual medical expenses per individual, demonstrating the importance of exploring ways in which they can be cared for in healthcare systems.[33]

2.7.3 Socioeconomic Status and Social Risk Factors

Lower socioeconomic status has been found to be associated with greater levels of UEC use by C&YP.[35] One reason to explain this association is discussed in a study suggesting that C&YP with the lowest socioeconomic status (aggregating household unemployment, overcrowding, lack of a car and occupation) were almost four times more likely to be

admitted to hospitals for injury related reasons such as pedestrian traffic collisions, burns/scalds, poisonings and general accidental injuries, in comparison to C&YP with the highest socioeconomic status.[36] Further to this, studies have also explored the association between ED use by C&YP residing in the most deprived areas and lack of access to primary healthcare services. For example, one study conducted in Canada found that access to a primary care physician was a significant predictor of low severity ED use amongst C&YP.[37] Although this is not directly explored within the UK, lack of access to (or delays in obtaining) GP appointments by parents and caregivers due to reasons such as high demand for primary care services in more economically deprived areas may specifically be contributing to higher utilisation of UEC services which usually require no appointment. Studies have also shown that C&YP living with social risk factors (defined by measures of food insecurity, risk of homelessness and parental partner violence) were associated with higher rates of ED use and subsequent hospitalisation.[38] However, this study also explored whether social risk factors could predict the time to next acute care episode but found no statistically significant association. Further social risk factors such as whether the child had been exposed to maltreatment has also been found to substantially increase the risk of ED visits during childhood and early adulthood.[39] This highlights the importance of safeguarding measures being in place within the UEC system and beyond to flag potential opportunities for relevant services to intervene.

2.7.4 Continuity of Care

In addition to the lack of availability of primary care services in more economically deprived areas, factors such as greater continuity with a primary care physician in more affluent areas have been found to be associated with reduced use of EDs and fewer hospital admissions. In one study conducted in Norway, a negative correlation was found between the duration of a

named regular GP and patient relationship and the use of out-of-hours services, acute hospital admission and mortality.[40] As the GP partner workforce has been shrinking since 2015 and GP growth stagnating for many years, continuity of the personal relationship between the patient and their general practice has significantly fallen in the UK.[41] The importance of continuity of care is highlighted in a study which suggests that the government's emphasis on access to GPs should also incorporate an ambition to improve continuity of care, in turn improving clinical outcomes and cost-effectiveness.[42]

2.7.5 Cultural Norms and Expectations of Healthcare

As the UK is a multicultural region containing individuals from a wide variety of ethnic backgrounds, cultural norms and expectations of healthcare services play an important role in UEC service use. Each ethnicity group brings its own perspectives and values to the healthcare system, with many beliefs and practices differing from traditional British healthcare culture. Such differences may affect patients' attitudes about healthcare and their ability to understand, manage and cope with the course of an illness, the meaning of a diagnosis and the consequences of medical treatment.[43] For example when considering migrant patients, cultural, religious beliefs and practices in their home country of birth/origin are likely to influence their individual perception of health. However, factors such as experiences of discrimination in healthcare settings, insecure immigration status, lack of healthcare information in the patient's preferred language and lack of trust and relationship-building between patients and healthcare professionals also play a pivotal part in healthcare use by this demographic. Hence, one government advisory report suggests that healthcare professionals should be aware of cultural beliefs impact on an individual's health, be aware of their own beliefs and biases, and actively discuss and manage the patient's treatment plans whilst respecting their beliefs.[44]

2.8 High Frequency Emergency Department Attendance

2.8.1 Introduction to High Frequency Emergency Department Attendance

Individuals that attend EDs on multiple occasions within a specified period comprise a relatively small proportion of the ED patient population but often account for a large proportion of all ED attendances.[45] Although definitions and attendance number thresholds for high frequency ED attenders vary across studies, one study suggested that a frequency of more than 4 ED attendances per year likely corresponded to non-random events.[46] This meant that high frequency ED attendance was unlikely to be random, implying these individuals often display common characteristics. One systematic review suggests the demand-driven consequences of high frequency ED attendance has been the focus of interest and concern in emergency medicine and health policy for at least four reasons.[47] First, the high number of attendances made by high frequency ED attenders have led to concerns about their appropriateness, which in the context of chronically overcrowded EDs has the potential to negatively impact the quality of care patients receive. Second, high frequency ED attenders generate high health costs. Third, high frequency ED attenders are often more likely to be vulnerable, isolated and live in more deprived areas in comparison to infrequent or non-users of EDs. These individuals are also more likely to report chronic medical conditions and often have higher mortality rates. Fourth, due to confounding factors associated with high frequency ED attendance, it is unclear why some patients overuse EDs.

2.8.2 High frequency Emergency Department Attendance by Children and Young People

Unlike adults, high frequency ED attendance by C&YP is often as a result of decisions made by parents and caregivers. In particular, factors such as parental healthcare anxieties have

been highlighted as an important consideration of high frequency ED attendance by C&YP. This is demonstrated by one study conducted in Canada which found ED use to be higher in infants under the age of one if their mother had made multiple ED attendances before pregnancy.[48] C&YP whom frequently attend EDs represent a highly vulnerable, outwardly challenging and remarkably diverse patient population.[49] Hence, NHS guidance states these patients should be treated with the same care and respect as other patients, triaged according to their presenting need, and provided with a bespoke ED care plan if necessary.[49]

2.9 Interventions to Modify Demand

Demand for UEC services is reaching all-time highs, and reducing the strain on the UEC sector has been a priority of the NHS for the last decade. In 2013 the NHS began the rollout of NHS 111, with one of the main aims of the telephone triage service to reduce strain on UEC services by ensuring patients are directed to the most appropriate service for their healthcare need.[50] However, studies conducted during the early years of the telephone triage service suggested that the anticipated substantial reduction in other parts of the UEC sector did not happen.[51] Specifically, one study concluded that in its first year of operation (in four pilot sites) there had been a 2.9% increase in emergency ambulance incidents and activity of UEC services in general (ranging from 4.7%-12% a month across the pilot sites).[51] Due to increased demand for primary care services, research has shown that patients who are directed to these services by NHS 111 may find it difficult to obtain an appointment - therefore resulting in increased use of other UEC services such as EDs.[13]

In recent years, a number of studies have explored and discussed methods of reducing demand for UEC services. In 2021, the NHS produced an action plan to help ease pressures on UEC services, and specifically focused on post-pandemic related issues constraining capacity to manage such demand (with examples including staff isolation and infection

prevention and control measures).[52] The plan concluded that there were a number of interacting and complex challenges within the UEC system, and a holistic and integrated approach may be the only method to ensure a strong recovery following the pandemic.[52] The plan contained ten action points designed to improve the quality of healthcare provided by the NHS and stated that support must be given to the following healthcare services: 999 and emergency services, NHS 111 services, primary care services, community health services and UTCs. In addition to this, the action plan also suggested that the increased use of healthcare services by C&YP must also be addressed.[52]

2.9.1 Healthcare as a Complex System

A complex system (in the context of UEC) comprises patients, ED staff, other healthcare services and the wider social setting. Studies have shown that UEC use display characteristics and statistical features of large complex systems, meaning interventions to manage demand should address drivers of consultations across the whole healthcare system rather than focusing solely on one area.[53] For example one study exploring healthcare use in Australia outlined how clinical practice guidelines intended to improve quality of care and reduce healthcare variations did not reduce socioeconomic disparities in the treatment of conditions such as diabetes, and in fact caused the unintended consequence of increasing the cost of medications of patients with multiple chronic conditions.[54] Frequent attendance is typically thought of as a problem of particular individuals, but similar patterns are seen in many naturally occurring complex systems. Hence in the context of managing high frequency ED users, care must be taken when addressing individual frequent attenders by considering potential unintended consequences elsewhere in the system.[55] This point is reiterated by a best practice guideline report produced by the Royal College of Emergency Medicine which suggests that reduction in absolute number of attendances made by frequent attenders is

unlikely to be an effective marker of intervention for this group and focus should actually be place on ensuring consistent care and reducing harm in the ED.[56]

2.9.2 Interventions to Modify Demand in Children and Young People

In January 2023 the Royal College of Paediatrics and Child Health published a report commenting on the published NHS action plan.[57] This report welcomed a number of solutions outlined to improve paediatric UEC. These include:

- The expansion of the advice provided through NHS.UK, NHS111 online and virtual wards to support decision making for young people and their families.
- More paediatric specific input for C&YP embedded within NHS 111.
- The national roll out of a paediatric early warning system (designed to track the deterioration of C&YP in hospitals) and paediatric respiratory hubs.

However this report also suggests that more needs to be done to improve the provision of UEC as a number of children were waiting more than 10 hours for treatment in EDs, with an average of just 30 paediatric critical care beds available across the country in December 2022, and NHS 111 calls rocketing.

2.10 Research Aims

The overarching aim of this PhD is to use routinely collected patient data to provide insights into how C&YP use EDs and other UEC services. Currently there is a clear lack of evidence exploring UEC pathways made by C&YP following contact with NHS 111 within the UK. This section has also highlighted the need for further research to examine high frequency ED use by C&YP in the UK, with specific emphasis placed on both medical and non-medical factors associated with this. These aims will be addressed through the quantitative analysis of

a large database of electronic health records to provide novel insights into the use of UEC services by C&YP in the UK.

2.11 Healthcare Data Research

To help provide policy makers with potential interventions to improve the provision of healthcare, research in health sciences has increased significantly in recent years. In particular, due to the nationwide adoption of electronic health records (EHRS) within clinical settings, this has provided opportunities for healthcare research using big data.

2.11.1 Philosophy of Science in Relation to Healthcare Data Research

Philosophical approaches to healthcare research can be split into several schools of thought, each concerning the ontological stance by which research should be conducted.[58] These schools of thought are generally divided into two broad philosophical systems, positivism and interpretivism. Positivism assumes that knowledge is independent of the subject being studied, and interpretivism assumes that individual observers have their own perception of reality.[58] The research conducted over the course of this PhD can be best described as positivistic, due to the quantitative and objective nature of analyses. Moreover, since this quantitative analysis will specifically consider secondary EHR data previously collected within the healthcare setting, there is an overarching assumption that this data truly measures reality (consistent with the positivistic philosophical approach to research). Although this PhD will specifically attempt to describe objective truths regarding the nature of UEC use by C&YP through quantitative data analysis techniques, this positivistic approach is limited to finding statistical correlations within these individuals. Hence, further understanding of why C&YP use UEC services may require more in-depth, qualitative techniques through closer interactions with these patients. A further limitation of the positivistic approach in relation to

the healthcare data research conducted during this PhD is the assumption that data is accurate. In practice, due to human involvement in processes such as data collection and measurements, errors within this type of data can occur. Although data analysis techniques can be implemented to find and remove obvious errors within the data (such as boxplots to ascertain outliers), inaccuracies embedded in collected information can be impossible to locate. It is for this reason that results produced using secondary data can only be as accurate as the data being analysed. This being said, when results were disseminated during the course of the PhD, this data validity claim is stated, thus allowing repetition and further experimentation to be conducted (following the scientific method, encompassed within the positivistic approach to research). In addition to philosophical arguments for and against the use of healthcare data research in this PhD, a number of other advantages and disadvantages exist.

2.11.2 Strengths of Healthcare Data Research

For the research objectives outlined in this PhD, analysis of EHRs has been chosen to best evaluate UEC use. Since this PhD is tasked with exploring the use of UEC services by C&YP, EHRs collected within the healthcare setting provide crucial information that could not be captured at scale using primary data collection methods. As well as being more time and cost-efficient than primary data collection methods, the range of variables collected in EHRs is greater than what could easily be collected otherwise. For example, if a parental survey was conducted (within a paediatric ED) to ascertain whether they contacted NHS 111 prior to attending, useful information such as call disposition, previous attendance history and call length may be omitted. Hence when considering the PhD research objectives, EHRs are likely to contain more detailed information collected over a longer period of time. In addition to the benefit of having a large sample size and range of variables available, EHRs also allow

for patient data to be linked across datasets. This was pivotal when evaluating the use of UEC services in C&YP, as the research objectives in this PhD contain a number of different healthcare services such as NHS 111 and EDs. Data linkage methods ensured a patient's UEC journey could be examined over the time period included for the data.

2.11.3 Limitations of Healthcare Data Research

A number of limitations exist when using EHRs in healthcare research. One such limitation is the existence of missing data. When dealing with binary data for example, although the presence of a 'yes' code will usually indicate the event occurred, confusion may arise in the absence of a code as this may indicate that the event did not occur when in reality information had not been inputted. Hence, data cleaning methods are extremely important in healthcare data research and can come with its own challenges when dealing with missing values. Although missing data can cause sample size implications within studies, lack of data may also introduce bias within research, as certain patients may be more likely to have statistics recorded in EHRs. For example, within routine primary care data, body mass index (BMI) may be more likely recorded in overweight individuals in comparison to average-weight individuals.[69] Hence, when conducting research using EHRs it is usually advisable to compute a sensitivity analysis and other widely recognised methods when deriving insights from data with missing values.

2.12 Data Used in this PhD

Due to the reasons discussed in this section, the exploration of the proposed PhD research aims will benefit from the use of EHRs in the form of routinely collected UEC data provided in the CUREd research database. Therefore, the CUREd research database will be introduced and described in the following section.

2.13 The CUREd Database[1]

2.13.1 Description of the CUREd Database

The CUREd research database is a large and unique linked research database comprising healthcare information for approximately one-tenth of England's population (across the Yorkshire and Humber region). This database consists of NHS 111 calls, Ambulance incidents, ED, Admitted Patient Care episodes and Provider Spell datasets, containing over 23 million linked patient episodes of care, between April 2011 and March 2017. For the analysis in this PhD, the NHS 111 calls, Ambulance incidents and ED datasets were analysed.

2.13.2 Research Ethics

Formal University of Sheffield Ethics Committee approval was obtained for the work conducted in this PhD. The data used in this PhD project is secondary, anonymised patient data from the "connected health cities" study and falls within the ethical approval granted for the CUREd database. The CUREd database has approval from the Leeds East National Health Service (NHS) Research and Ethics Committee (18/YH/0234) and from the NHS Health Research Authority's Confidentiality Advisory Group (18/CAG/0126). The School of Health and Related Research Ethics committee approved the work conducted in this PhD (reference number 046123 dated 19/04/2022). The main ethical considerations for the studies conducted were related to the management of large datasets and data protection. In managing a large dataset I was adequately trained in data management. I completed the ScHARR information security training which includes training on: protecting information, protecting

[1] Information regarding the CUREd database was obtained via the Centre for Urgent & Emergency Care Research website accessed through the School of Health and Related Research within the University of Sheffield.

personal data, protecting research data, and information governance. This training was important for each of the studies undertaken in this PhD. To ensure data security, all data provided by CUREd was secured on a University of Sheffield password protected network that was only accessible by me. Permission to use the CUREd data for the purposes of this PhD was granted by the data release committee, and a collaboration and information-sharing agreement was signed between CUREd and Akshay Kumar prior to accessing the data. The information-sharing agreement was signed to ensure that only high-quality research was undertaken using the CUREd data, and that the research conducted would in no way harm participants.

2.13.3 Patient and Public Involvement

Patient and Public Involvement (PPI) in research is an integral part of healthcare research in the UK.[59] The key features of PPI are that research should be carried out 'with' or 'by' members of the public rather than 'for' or 'about' them.[60] NHS guidance indicates that where possible service users and representative groups should be involved in the research process. PPI involvement in research is largely undertaken for methodological, moral/ ethical or political reasons. Methodologically, involving patients in research has the potential to improve the quality, transferability and credibility of the research findings.[61] Public involvement in research is also seen to be a democratic principle, in that people who are affected by research should be able to influence how publicly funded research is undertaken.[60] There is an expectation from many funding bodies that researchers consider involving patients in their work.[60] Although the studies for this PhD did not propose to include patients, PPI plays a pivotal part in the conceptualisation and collection of the CUREd research database and involves a Data Release Committee (DRC) which acts as an

oversight panel for the CUREd platform including patient and public representation, health care stakeholders, and information governance specialists.

2.13.4 General Data Protection Regulation (GDPR) for the CUREd Dataset

- **Lawfulness, Fairness and Transparency**: The CUREd research database lawfully collates routine NHS data from NHS UEC service providers. Patients have the opportunity to opt out of data collection if they prefer for their information not to be included in the CUREd dataset. This process is confidential and secure-withdrawing data from the study does not preclude the patient from further studies and will not affect their treatment.
- **Purpose Limitation**: In line with the principle of transparency, data can only be used for specific purposes. The CUREd DRC was created to review all requests for data extracts from the CUREd database. The purpose of the CUREd DRC is to provide stewardship to help maintain high standards, as well as providing a voice for stakeholders and the public. The DRC ensure that the data must only be used for research purposes that align with the aims of the research database (i.e. used for research in UEC).
- **Data Minimisation**: The DRC ensure that only data required in the study is provided to the investigator. In addition to this, identifiable information was only be kept for the minimum amount of time possible until data linkage and validation of data linkage had taken place. Following this stage, personal identifiable information was removed from the CUREd Research Database and replaced by a unique identifying number.
- **Accuracy**: The CUREd research database contains linked data across a number of UEC services. Due to the presence of common, high quality identifiers (such as NHS numbers) data linkage was accurate with the results openly available to the public.

- **Storage Limitation:** The terms and conditions for data transfers, storage and processing states that CUREd data should be returned or destroyed on termination of the Data Sharing Agreement or upon request from the University of Sheffield. The investigator is also expected to retain the CUREd data in a secure location at the institution.
- **Integrity and Confidentiality:** All patient identifiable information, such as names, addresses and dates of birth of patients, was stored on a virtual machine that is isolated from all other computer systems and is protected by digital access control and other security systems, so that the risk of unauthorised access to this information by anyone is extremely low. This system is also physically locked down and is only accessible by authorised personnel.

2.14 Chapter Summary

Demand for UEC services by C&YP has been increasing in recent years, with the remnants of the Covid-19 pandemic only exacerbating this problem.[62] This background section has outlined the importance of understanding why parents and caregivers choose to attend UEC services such as the ED when their child requires healthcare treatment. In the UK the telephone triage service NHS 111 plays an important role when assisting parents and caregivers with healthcare decision making, and is therefore directly linked to the use of other UEC services by C&YP. In addition to the importance of NHS 111 and UEC service use by C&YP, this section has also outlined the importance of exploring the phenomenon of high frequency ED attendance in C&YP. Although high frequency ED attendance in adults has been examined in previous literature produced in the UK, less is known about high frequency attendance in C&YP.

This PhD has the overarching aim of providing novel insights into UEC use by C&YP using the CUREd research database. However, to help focus the research questions addressed using the large database, two systematic reviews were conducted. These review questions were derived from a combination of background reading (outlined in this section) and discussion with medical professionals within the primary and secondary healthcare sectors and are concerning:

- The use of NHS 111 or equivalent telephone triage service by C&YP prior to an ED attendance
- High frequency ED attendance by C&YP

3 The Use of NHS 111 and Other Telephone Triage Services Prior to an Emergency Department Attendance by Children and Young People: A Systematic Literature Review

3.1 Chapter Outline

The background chapter outlines the value of telephone triage services for parents and caregivers concerned about the health of their child. Due to the specific importance of NHS 111 as an initial point of contact for parents and caregivers in the UK, this was chosen as an area of research in this PhD. Hence, this chapter outlines the first of two systematic literature reviews conducted during this PhD, and was tasked with determining what had previously been published in relation to the use of telephone triage services prior to an ED attendance by C&YP. This systematic review synthesises data collected from a number of studies produced around the world and is presented in the format of a manuscript. The motivation behind this literature review was to determine what had previously been published in the subject area, but also to highlight evidence gaps to focus the research conducted in this PhD.

3.2 Background

Telephone triage services are utilised by parents and caregivers to ascertain the severity of their child's healthcare needs, and determine which services should be accessed to provide treatment.[63] Within the UK, NHS 111 is frequently used by parents and caregivers, with more than 3.5 million calls made in the Yorkshire and Humber region alone between the years 2013 and 2017.[64] Although a main aim of NHS 111 is to ensure users are directed to the most appropriate service for their healthcare need, there have been concerns regarding the effectiveness of the telephone triage service due to an increased number of ED attendances in those provided with a call disposition.[65] If a large proportion of these individuals do not

require the facilities of UEC services, this can cause strain on resources which can lead to overcrowding and longer waiting times for individuals in need of urgent care.[16] However, when assessing the effectiveness of telephone triage service, factors such as compliance with call advice should be considered. This is demonstrated by one study which found that although a proportion of NHS 111 calls advised the use of primary care services such as GP practices, a number of these calls still resulted in an ED attendance.[64]

The main objective of this systematic literature review is to determine what has been published on the relationship between telephone triage services such as NHS 111 and subsequent ED use in C&YP. In particular, it aims to review publications exploring characteristics of call subjects (including the medical symptoms C&YP exhibit) when parents/caregivers seek healthcare advice from non-emergency medical telephone triage services, compliance with the advice provided during calls, and the proportion and appropriateness of call related ED attendances.

3.3 Methods

3.3.1 Systematic Review Guidelines

Standard approaches for systematic reviews were adopted and reported against PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines.

3.3.2 Review Objectives and Sub-questions

The main objective of this systematic review was to ascertain "What evidence had been published in relation to the use of NHS 111 or other telephone triage services for C&YP prior to an ED attendance." In addition to this, the following sub-questions were proposed:

- Are NHS 111 and/or equivalent telephone triage services useful in directing C&YP to UEC treatment pathways?
- Do parents and caregivers of C&YP comply with ED advice (both clinical and non-clinical) provided during calls?
- What outcomes are being measured to determine the effectiveness of telephone triage services?

3.3.3 Search Strategy

It was decided that the databases: Medline, CINAHL and Embase (hosted by Ovid and Ebsco) were to be searched. These databases were specifically chosen to ensure relevant emergency healthcare and paediatric journals (such as The Emergency Medical Journal, Annals of Emergency Medicine, The Journal of Pediatrics and Archives of Disease in Childhood) were included. This reduced the likelihood of relevant publications being omitted. A set of eligibility criteria were formulated using the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research type) framework for systematic reviews, chosen to ensure specific study designs could be clearly defined.[66] For this systematic review, publication inclusion criteria included: the population age of 21 and under (not limited to the UK), ED or paediatric ED setting and quantitative cohort studies. The population age of 21 was chosen as an upper limit definition of paediatrics based on the American Academy of Paediatrics definition, as some studies were produced in the USA.[67] Specific details of the eligibility criteria for this review question are provided in Table 1.

Table 1-Use of Telephone Triage Service SPIDER Framework

SPIDER Framework	Description	Search Terms

Sample	Patients who attended EDs after calling NHS 111 or telephone triage service were included in the systematic review. Sample population was not limited to the UK and could include any ages between 0-21.	"Child*" OR "Young people" OR "Paediatric*" OR "Pediatric" OR "Baby"
Phenomenon of **I**nterest	ED use after NHS 111 or telephone triage service was called. Parental compliance to advice provided in calls.	("telephone triage" OR hotline* OR "telephone triage and advice services" OR advice-service* OR "teleconsultation" OR "telenursing" OR "NHS 111" OR "NHS 24" OR "NHS Direct Wales" OR "NHS Direct" OR "clinical-support-system*") AND ("accident and emergency" OR "accident & emergency" OR emergency service? OR "casualty" OR "casualty ward" OR "ER" OR (emergency adj2 (care OR healthcare OR department? OR unit OR units OR room? OR treatment?)))
Design	Cohort studies using previously collected data.	(cohort adj (study or studies)).ab,ti. OR (observ$ adj3 (study or studies)).ab,ti.
Evaluation	Evaluation factors/variables of interest including ED attendances, length of stay and avoidable attendances (after NHS 111 or equivalent telephone triage service were called) Patient characteristics such as acuity of ED attendance, sex, socioeconomic factors, length of helpline call and provision of clinical advice.	Checked via screening
Research Type	Study design must be cohort studies and thus should be quantitative analysis.	(cohort adj (study or studies)).ab,ti. OR (observ$ adj3 (study or studies)).ab,ti.

3.3.4 Search Terms

For this systematic review, a set of search terms were chosen and adapted for Medline via Ovid, and CINAHL via Ebsco (as terms needed to be manipulated for each database due to differing Boolean operators and notation). Since this systematic review was chosen to include publications outside the UK, alternative search terms were required to account for differences in medical jargon and general spelling. For example, in countries such as the USA, papers were more likely to use terms such as an 'emergency room' (ER) rather than an 'emergency department' (ED) and authors are more likely to spell 'paediatric' as 'pediatric'. These alternative terms were derived using a number of methods such as: discussion with medical experts, searching relevant publications and exploring online medical dictionaries. The derived list of search terms for this review question is provided in Table 2.

Table 2-Use of Telephone Triage Service Search Terms

Medline via Ovid search terms
("telephone triage" OR hotline* OR "telephone triage and advice services" OR advice-service* OR "teleconsultation" OR "telenursing" OR "NHS 111" OR "NHS 24" OR "NHS Direct Wales" OR "NHS Direct" OR "clinical-support-system*")
AND ("accident and emergency" OR "accident & emergency" OR emergency service? OR "casualty" OR "casualty ward" OR "ER" OR (emergency adj2 (care OR healthcare OR department? OR unit OR units OR room? OR treatment?)))
AND "Child*" OR "Young people" OR "Paediatric*" OR "Pediatric" OR "Baby"
CINAHL via Ebsco search terms
telephone triage or telephone assessment* or telephone advice or hotline* or helpline* or advice service* or teleconsultation* or telemedicine or telecare or telehealth or telenursing or nhs 111 or nhs 24 or nhs direct wales or nhs direct or clinical support system*
AND emergency department or emergency room or accident and emergency or accident & emergency or a&e or a & e or emergency medical service* or casualty or casualty ward* or er or ed or emergency care or emergency nursing or emergency healthcare or emergency unit* or emergency treatment*
AND Child* or Young people or Paediatric* or Pediatric or Baby

3.3.5 Study Selection

After the above search string was conducted in Medline (using the Ovid database), Embase and CINAHL (using the EBSCO database), the corresponding publications were transferred to Endnote to allow for paper screening. The screening process excluded papers based on the relevancy of the title, abstract and then full text. This was conducted by one person, with queries checked with the broader supervision team. Although the initial search in both Ovid and Ebsco was limited to English language publications, some papers only provided English abstract translations meaning full texts were still in a non-English language. These, alongside publications where full papers were not accessible (after searching through Endnote links, supervisor access or university library support teams) were also omitted from the final selection (see prisma diagram, Figure 1).

3.3.6 Study Quality Assessment and Risk of Bias

A critical appraisal tool was used to assess the quality of the included studies. Since the publications were selected to only include cohort-based studies in this review, the tool was chosen to be the "NIH Quality Assessment tool for Observational Cohort and Cross-Sectional studies". This consisted of fifteen questions alongside question guidance. Each question was answered with either a 'Yes (Y)', 'No (N)', 'Not reported (NR)' or 'Not Applicable (NA)'. To provide a definitive answer as to the quality of the study, if the study produced:

- 0-4 'Yes' answers out of the 15 questions the study was rated as poor.
- 5-10 'Yes' answers out of the 15 questions the study was rated as fair.
- 11-15 'Yes' answers out of the 15 questions the study was rated as good.

Publications defined as poor using the study quality assessment tool, were omitted from the systematic review. Studies defined as poor had a high likelihood of bias, whereas fair and good studies were less likely to contain high levels of bias.

3.3.7 Data Extraction

For the data extraction procedure in this systematic review, Microsoft Excel was used, and an extraction document was produced. This document consisted of the following extracted information: Author, publication year, study site, setting of data, data collection method, country/area of data origin and main paper objectives, sample size, sample age group, parental compliance, ED referral rates, frequent complaints, ED visit appropriateness, telephone triage name and telephone triage setting.

3.4 Results

The search strategy produced a total of 896 publications for this systematic review. Of these, 18 were deemed relevant after initially screening the abstract. 2 publications had no available full English language paper[2] to screen and 7 were deemed irrelevant after screening the full text, and were omitted from the final publications. Hence 9 publications were included in the final selection and were assessed using the NIH quality assessment tool. All 9 papers passed the check, meaning the risk of bias in the publications was likely to be low. A total of 4 papers were deemed good, 5 fair and 0 poor (see Table 3). These 9 papers were then analysed, and relevant data was extracted using Excel.

3.4.1 Characteristics of Included Studies

The final selection of included studies for this review question consisted of nine publications. Of these studies, there was variation between a number of study characteristics such as the year of publication, country (and city/state) of origin and the total sample size (Table 4).

[2] If publications could not be accessed via links and DOIs provided by the search platforms or through university credentials, the university library and/or authors were contacted. Publications were then omitted if full English papers could not be retrieved.

Table 3-NIH Quality Assessment Check NHS 111

NIH Quality Assessment Check

Y, yes; N, no; *CD, cannot determine; NA, not applicable; NR, not reported

	Was the research question or objective in this paper clearly stated?	Was the study population clearly specified and defined?	Was the participation rate of eligible persons at least 50%?	Were all the subjects selected or recruited from the same or similar populations (including the same time period)?	Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Was a sample size justification, power description, or variance and effect estimates provided?	For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Was the exposure(s) assessed more than once over time?	Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Were the outcome assessors blinded to the exposure status of participants?	Was loss to follow-up after baseline 20% or less?	Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Quality
NHS 111:																
Al-Abdullah, T. et al, 2009	Y	Y	NA	Y	Y	Y	Y	Y	Y	Y	NA	Y	NA	NA	Y	Good
Bolli, S. et al, 2005	Y	Y	Y	NA	Y	Y	Y	Y	Y	Y	Y	Y	NA	NA	Y	Good
Crane et al, 2000	Y	Y	NA	Y	NA	Y	Y	Y	NA	Y	NA	Y	NA	NR	NR	Fair
Kempe, A et al, 2003	Y	Y	Y	Y	Y	Y	Y	Y	NA	Y	NA	Y	NA	Y	Y	Good
Light. P. A et al, 2005	Y	Y	NA	Y	NA	N	Y	Y	NA	Y	NA	Y	NA	NA	NA	Fair
Molyneux. E et al, 1994	Y	Y	NR	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NR	Y	Good
Robinson et al, 2017	Y	Y	NA	Y	NA	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Stewart, B et al, 2006	Y	Y	NA	Y	NA	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Turbitt, Erin et al, 2015	Y	Y	NR	Y	NR	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair

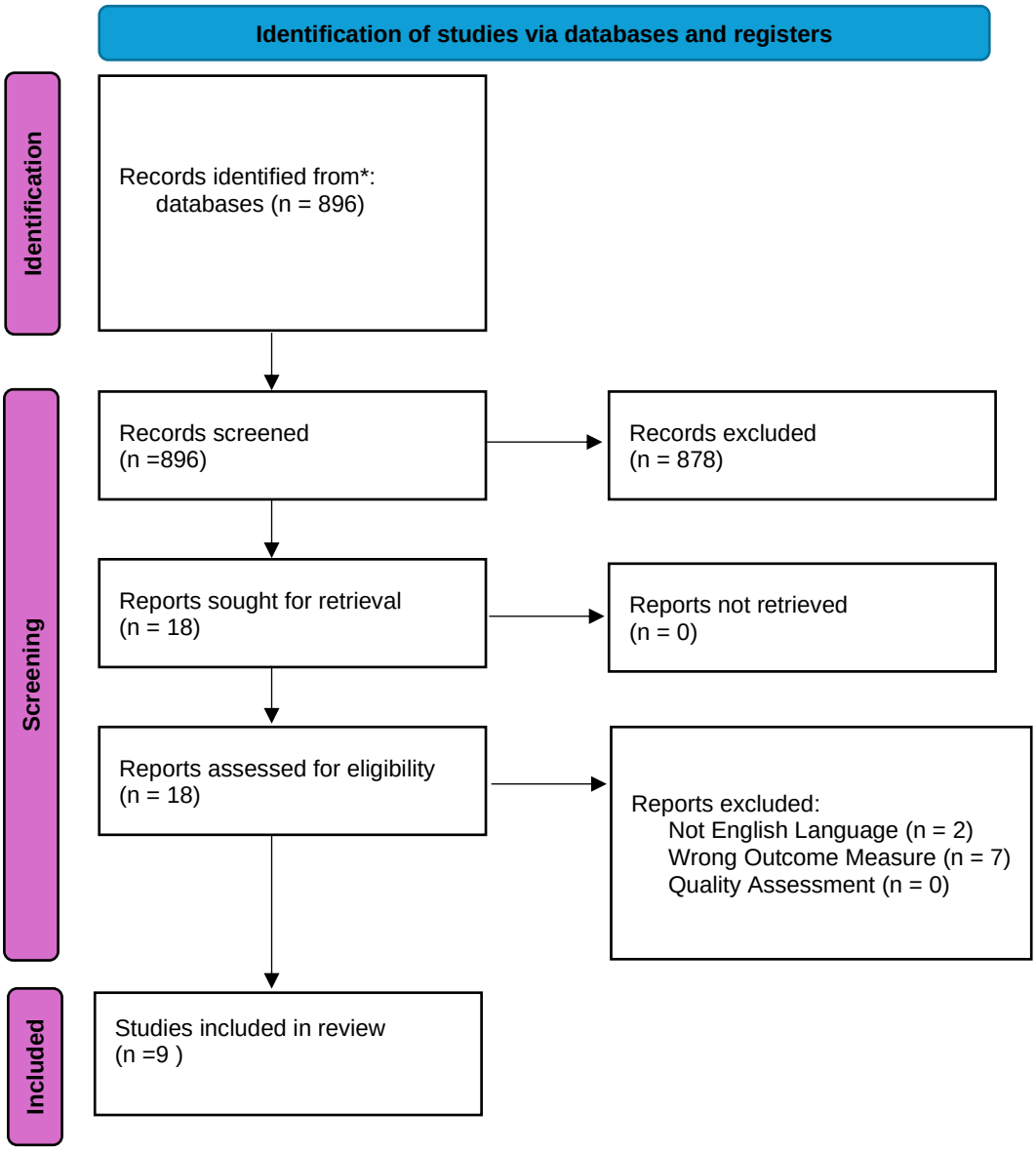

Figure 1-PRISMA Diagram NHS 111 Systematic Review

Table 4-Characteristics of Included Studies

Author	Publication Year	Country	City/State	Total sample size	Age	Data collection site	Primary data collected	Study objective
Al-Abdullah [68]	2009	Canada	Ontario (Ottawa)	578	0-18	ED	No	Helpline use and appropriate ED visits
Bolli [69]	2005	Switzerland	Neuchatel	7870	0-18	ED	Yes-survey	call characteristics
Crane [70]	2000	USA	Augusta (Georgia)	493	0-18	ED	No	parental compliance
Kempe [71]	2003	USA	Multiple States	1561	0-18	Call centre	Yes-survey	parental compliance
Light [63]	2005	USA	-	110	1-2	Call centre	No	parental compliance
Molyneux [72]	1994	UK	Liverpool	764	0-22	ED	No	call characteristics
Robinson [73]	2018	UK	London	11279	0-15	Call centre	No	call characteristics
Stewart [74]	2006	UK	North-West England	3312	0-16	Call centre	No	parental compliance
Turbitt [75]	2015	Australia	Victoria	1150	0-9	ED	Yes-Survey	general call characteristics

Study location was mostly limited to North America [63, 68, 70, 71] and the UK [72-74], with only two publications exploring data collected outside these regions.[69, 75] Eight publications limited the study age to under eighteen [63, 68-71, 73-75], and one publication analysed data from individuals under the age of twenty-two.[72] Five publications used secondary data previously collected within EDs [68-70, 72, 75] and four publications used data previously collected from telephone triage service call centres.[63, 71, 73, 74] Although all included studies used secondary data, three studies also used primary data collected via the use of surveys.[69, 71, 75] The main objective of the included publications explored either general telephone triage call and/or subsequent ED attendance characteristics [69, 72, 73, 75], or compliance with the advice provided during calls.[63, 70, 71, 74] One publication also analysed the appropriateness of ED visits following contact with a telephone triage service.[68]

3.4.2 Telephone Triage Service Call Characteristics

Publications exploring telephone triage call characteristics as a main objective identified a number of descriptive attributes. These include the most common patient age groups, telephone triage setting and call complaints (see Table 5).

Table 5-Call Characteristics

Author	Most common age group	Telephone triage service setting	Telephone triage operator name	Main call complaint
Al-Abdullah [68]	-	Within specialist call centre sites	Telehealth Ontario	-
Bolli [69]	<1 (23%)	Within hospital	-	Fever, Earache
Crane [70]	<1 (41.6%)	Within hospital	-	Fever, Respiratory complications
Kempe [71]	-	Within hospital	-	-
Light [63]	17 Months	Within specialist call centre sites	The Children's Careline	-
Molyneux [72]	<1 (20%)	Within hospital	-	Accidental ingestion, Head injuries
Robinson [73]	-	Within specialist call centre sites	NHS 111	-
Stewart [74]	<1 (20%)	Within specialist call centre sites	NHS Direct	Respiratory complications
Turbitt [75]	<1 (23%)	Within specialist call centre sites	Victorian Nurse-on-call	-

3.4.2.1 Age Groups of Patients

Six publications provided information regarding the age demographic of call subjects. In general, these studies agreed that calls were regarding younger children, with five studies reporting that call subjects were likely to be under the age of one.[69, 70, 72, 74, 75] Additionally, one study also found that the modal call subject age was 17 months old.[63]

3.4.2.2 Telephone Triage Service Setting

Calls to telephone triage services were either taken by call handlers managing attendances for an affiliate ED [69-72], or by call handlers located within specialist call centres providing non-emergency medical advice for individuals living in a specific geographical region.[63, 68, 73-75] Although information was provided regarding the setting of the telephone triage service, additional information such as the professional background of the call handler and whether electronic disposition algorithms were utilised during calls were not included in these studies.

3.4.2.3 Main Call Complaint

Of the four publications reporting the main call complaint described during calls, the most common complaint was regarding respiratory complications.[70, 74] Although specific details of the respiratory complications described during calls were not provided in these studies, as fever was also reported as a common call complaint [69, 70], parents and caregivers were likely to call telephone triage services when their child was suffering with an illness. In addition to illness-related call complaints, parents and caregivers were also likely to call telephone triage services when there was a head injury or accidental ingestion.[72]

3.4.3 Parental/Caregiver Compliance with Telephone Triage Advice

Parental/caregiver compliance with telephone triage advice was measured in a number of ways. The table below outlines the compliance definition used by studies (see Table 6).

Table 6-Parental/Caregiver Compliance

Author	Compliance when ED advised during call			Compliance when home care advised during call			Compliance to all dispositions provided during calls		
	n/N	%	95% CI	n/N	%	95% CI	n/N	%	95% CI
Crane [70]	86/92	93.5	[86.34%, 97.6%]	-	-	-	412/493	83.6	[80%, 86.73%]
Light [63]	-	-	-	88/110	80	[71.3%, 87.02%]	-	-	-
Molyneux [72]	174/259	67	[61.1%, 72.87%]	-	-	-	-	-	-
Robinson [73]	1331/2086	63.8	[61.7%, 65.87%]	-	-	-	-	-	-
Stewart [74]	299/460	65	[60.45%, 69.36%]	-	-	-	-	-	-

In general, compliance with the advice provided in calls was relatively high, with more than two-thirds of parents/caregivers complying with call dispositions across the studies exploring this.[63, 70, 72-74] Compliance when an ED visit was specifically advised varied, with 63.8% to 93.5% of parents/caregivers following the advice provided.[70, 72-74] This is presented graphically in the forest plot below and shows there is relatively high homogeneity with respect to compliance when an ED visit was advised (see Figure 2). That being said, one smaller study suggested a very large proportion of parents/caregivers followed the advice provided.

Figure 2-Forest Plot to Show Compliance with ED Disposition

Parental/caregiver compliance when home care was specifically advised was found to be high (80%).[63] One publication aggregated overall parental/caregiver compliance across all possible call dispositions (including next day GP appointments and ED attendance) and concluded that 83.6% of parents/caregivers followed the telephone triage advice.[70] These results suggest that parental/caregiver call compliance depended on the disposition of the call, with callers being more likely to follow the advice when home care was suggested in comparison to when ED was advised.

3.4.4 Appropriateness of ED Attendances after Telephone Triage

Although the appropriateness of an ED attendance after receiving advice from a telephone triage service was mentioned in five studies, how appropriateness was defined varied across these studies. One study deemed an ED attendance appropriate if a specific diagnosis (such as major medical arrest, trauma, acute allergic reaction and respiratory illness), symptom (such as fever over 39℃, severe pain and gastrointestinal illness) and/or parental concern (such as a history of pronounced irritability, lethargy, earache or vomiting) was observed.[68] On the other hand, one study used a clinical expert decision panel to retrospectively determine whether an ED visit call disposition was appropriate.[71] One study concluded that medical advice provided over the phone resulted in the prevention of many unnecessary ED visits [72], however this publication was produced in the UK in 1994 when telephone triage service providers were largely uncommon. Some publications agreed that clinical advice (provided by a clinician) during calls led to more appropriate ED visits.[68, 71, 73] In particular, the literature suggested that individuals referred to EDs by a non-clinical health line were more likely to lead to an inappropriate attendance in comparison to physician-referred patients.[68] Finally, one publication concluded that callers who spoke to a GP as part of the call episode were less likely to attend EDs than other callers.[73] The evidence in the literature therefore suggests that individuals were more likely to inappropriately attend an ED when no clinical advice (by a clinician) is provided during contact with a telephone triage service.

3.4.5 Updating The Literature Review Search

As this systematic review was completed in 2022, we re-ran the review search terms to include any relevant recently published studies. This produced one new publication.

3.4.5.1 Freiermuth, et al

This study was set in Switzerland between the 1st February 2022 to the 5th of March 2022, and analysed paediatric telephone triage calls provided with an ED disposition.[76] The aim of this study was to determine parental compliance with ED dispositions after being referred by the nurses of a call-centre, observe how compliance varies across different patient characteristics, and to determine parental reasons for non-compliance. Compliance with an ED call disposition was found to be 75% and therefore fell in a similar range to the figures found in this review across studies providing ED disposition call compliance. This study additionally found that compliance decreased significantly with increased distance between the place the call originated from and the ED. However, the child's age, sex and health complaints had no effect on compliance. The main reasons for non-compliance with the ED advice were improvement in the child's condition (50.7%), parents' decision to go elsewhere (18.3%) and an appointment with a paediatrician (15.5%).

3.5 Discussion

3.5.1 Summary of Main Findings

The main study objectives of the publications explored either call and/or subsequent ED attendance characteristics, parental/caregiver compliance with telephone triage advice provided during calls, or the appropriateness of ED visits following contact with telephone triage services. Call subjects were most likely to be younger children (under the age of one), suffering from illness-related symptoms such as respiratory complications and fever, or accidental injuries such as accidental ingestion and head injuries. Parental/caregiver compliance with the advice made during calls depended on the disposition provided. Parents/caregivers were less likely to comply with call advice when an ED disposition was provided, in comparison to when a home care disposition was provided. One study found that non-compliance with ED dispositions was largely due to the improvement in a child's condition, parents' decision to go elsewhere and/or an appointment with a paediatrician. Although an older study suggested that telephone triage services could reduce the number of inappropriate visits to EDs, newer publications have suggested that telephone triage services may be leading to a number of inappropriate ED attendances by C&YP (especially when the call did not involve input from a clinical expert).

3.5.2 Strengths and Limitations

Due to the relative consistency of the study objectives across included publications, similarities in reported measures ensured that data synthesis was possible. In particular, characteristics of call subjects (including common call complaints and call subject age groups) were provided in the majority of publications. As publications were not limited to geographical locations for this systematic review, a variety of telephone triage operators were

considered. It was therefore possible to examine similarities and differences between telephone triage services and subsequent ED use by C&YP in a number of different countries. Although compliance with the advice provided during calls was frequently explored, the definition of compliance varied across studies. When considering compliance with an ED disposition for example, studies used a variety of time thresholds to ascertain if a parent subsequently attended an ED with their child. Due to the heterogeneity between age groups, parental compliance definitions and the telephone triage settings considered in studies, more complex data syntheses and meta-analysis methods were deemed inappropriate. This being said, a forest plot was produced to help visualise parental compliance with ED dispositions provided during calls. Although the I-squared value was presented in the forest plots, a number of limitations exist regarding the measure. This includes the fact that it depends on sample size, outcome type (e.g. binary) and outcome rate, and is not strictly a measure of heterogeneity. While data was only formally extracted by one person, the searches and search outputs were discussed in detail during supervision and quantitative data extracted was reviewed by a supervisor for consistency and checking in the case of unexpected findings. Although exclusion criteria was used when searching for literature in this review, only the inclusion criteria was explicitly listed. As this systematic review excluded non-peer reviewed literature, grey literature including evaluation reports are likely to have been missed.

3.5.3 Relationship with Other Research

In addition to telephone triage services, digital and online health services have increasingly been implemented by national healthcare systems.[2] In the UK, NHS 111 has been extended to a digital platform providing similar support in the form of a free-to-access website. A systematic review published in 2019 assessed this online service and found the algorithm-

based triage was likely to be more risk-averse than health professionals.[77] This mirrors the result found in this systematic literature review suggesting that calls involving clinical expert input were less likely to result in an inappropriate ED attendance (in comparison to when a non-clinical call handler uses an algorithm for triage). Further information regarding the compliance with online non-emergency medical services could not be determined in the systematic review.

3.5.4 Implications for Practice, Policy and Research

As call subjects were most likely to be under the age of one, further research must specifically explore this age demographic to ascertain if contact with telephone triage services subsequently leads to appropriate healthcare pathways for the patient. Medical and non-medical factors associated with why parents and caregivers seek medical advice must also be explored in future research. This can help determine ways in which telephone triage services can be improved for this demographic. The evidence provided in this literature review suggests that C&YP may be directed to EDs when more appropriate healthcare services are available. This was found to be the case when clinical experts were not involved in calls, implying decision support algorithms may be too risk averse when directing patients to the ED. Further research must be conducted to distinguish the reasons behind why medical experts were more effective at determining the severity of calls in comparison to decision support algorithms, and whether the use of modern data analysis approaches such as machine learning and artificial intelligence can be further utilised to improve such algorithms.

Although parental/caregiver compliance with advice provided during telephone triage was explored by a number of studies, research could further explore the factors associated with why parental/caregivers decide not to follow the advice provided. This can help distinguish

between parents/caregivers who do not follow call advice when their child's medical need is resolved without further medical assistance, and those who choose not to comply because they disagree with the disposition provided. Further research could specifically consider a combination of the time taken to attend ED following contact with a telephone triage service, the advice provided during the call, and subsequent ED outcomes to provide further information regarding parents/caregiver decision making. This can provide insights into the effectiveness of telephone triage services when triaging patients to the most appropriate healthcare setting.

3.5.5 Conclusion

Telephone triage services are designed to reduce avoidable ED attendances by ensuring patients are directed to appropriate medical pathways. This review has found that telephone triage services may in fact be contributing to increased numbers of avoidable ED attendances in C&YP, even when compliance with call dispositions was relatively high. This being said, as medical expert input during calls was found to reduce avoidable attendances for C&YP, further research should explore the balance between the risk averse nature of telephone triage services, and the potential detrimental effects of directing a large proportion of individuals to EDs when other services may be more appropriate.

3.6 Chapter Summary and Evidence Gaps

This review provides key insights into the relationship between telephone triage and ED use in C&YP, and highlights a number of evidence gaps. The main evidence gap was the lack of NHS 111 related publications. Unlike telephone triage services in other countries, NHS 111 is unique as it is operated nationwide, and available to all parents/caregivers concerned about

their child's health. This, in combination with the potential strain increased demand for EDs has on the provision of UEC care for C&YP, means it is important to explore the effect NHS 111 has on other UEC services. In particular, although the systematic review identified one publication providing important considerations regarding the use of NHS 111 by C&YP (such as the association between clinical input during calls and lower rates of ED use), the study did not include callers advised to attend an ED by NHS 111. This provides the opportunity for future research to explore this relationship across a larger sample of individuals. No studies explore the time taken to attend EDs following contact with telephone triage services. This could be used to determine the decisions parents and caregivers make when attending EDs after contacting a telephone triage service for their child.

4 High frequency Emergency Department Attendance by Children and Young People: A Systematic Literature Review

4.1 Chapter Outline

A combination of background reading (outlined in the background section of this PhD) and discussion with medical practitioners and researchers has highlighted the importance of examining high frequency ED attendance by C&YP. Hence, whilst one aspect of this PhD explores the use of telephone triage and UEC services by C&YP, the other aspect was chosen to explore C&YP who frequently attend EDs. This chapter therefore outlines the second systematic review conducted during this PhD and was tasked with determining what had been published in relation to high frequency ED use by C&YP. Like with the first systematic review, the motivation behind this review was to highlight gaps in the evidence for this PhD to fill.

4.2 Background

The most common definition for a high frequency ED attender is an individual who visits the ED more than four times a year.[78] However, literature exploring high frequency ED attendance use a variety of definitions based on arbitrary numeric thresholds or percentiles over a prespecified time period.[79] In recent years, emphasis has been placed on addressing the needs of adult high frequency ED attenders with the goal of producing more cost-effective UEC services.[80] However, identifying factors associated with high frequency ED attendance can be challenging due to underlying heterogeneity within these patients. A UK study showed that a number of predictors of adult high frequency ED attendance exist, with 45% of these patients exhibiting medically unexplained symptoms, 15% having significant alcohol problems and 65% having mental health symptoms.[80]

In addition to high frequency ED use in adults, a proportion of C&YP classify as high frequency ED users. Differences between children and adult high frequency ED attenders may derive from contrasting biological profiles and healthcare needs, but may also associated with non-medical factors such as health-seeking behaviours (including healthcare perceptions of parents and caregivers).[81] ED attendances made by C&YP largely depend on healthcare decisions made by parents or caregivers (especially when the child cannot make healthcare decisions on their own).[29] Studies have suggested that caregivers' health literacy, overestimation of clinical urgency, and anxiety are associated with increased ED use in C&YP.[82] Although published literature has suggested that a proportion high frequency ED attenders may be likely to have chronic conditions, one study suggests the majority may be no sicker or more in need of hospital services than those who attend less frequently, and therefore make a number of avoidable ED attendances.[83] The objective of this systematic review is to bring together the evidence for high frequency ED attendance in C&YP. Specifically, we aimed to address the following review question:

- What is the prevalence of high frequency ED use in C&YP and which factors were associated with it?

4.3 Methods

4.3.1 Systematic Review Guidelines

Standard approaches for systematic reviews were adopted and reported against PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines.

4.3.2 Review Objectives and Sub-questions

The main objective of this systematic review was to ascertain "The prevalence of high frequency ED use in C&YP and which factors were associated with it". Further sub-questions proposed included:

- How are children and young high frequency ED users defined?
- What proportion of children and young ED users are high frequency ED attenders?
- What proportion of children and young high frequency ED users have long term medical conditions?
- What were the ED outcomes of children and young high frequency ED attenders?

4.3.3 Search Strategy

It was decided that the databases: Medline, CINAHL and Embase (hosted by Ovid and Ebsco) were to be searched. These databases were specifically chosen to ensure relevant emergency healthcare and paediatric journals (such as The Emergency Medical Journal, Annals of Emergency Medicine, The Journal of Pediatrics and Archives of Disease in Childhood) were included, therefore reducing the likelihood of relevant publications being omitted. A set of eligibility criteria were formulated using the SPIDER (Sample,

Phenomenon of Interest, Design, Evaluation and Research type) framework for systematic reviews, chosen to ensure specific study designs could be clearly defined.[66] For this systematic review, publication inclusion criteria included: the population age of 21 and under (not limited to the UK), general or paediatric ED setting and quantitative cohort studies. The population age of 21 was chosen as an upper limit definition of paediatric based on the American Academy of Paediatrics definition.[67] Specific details of the eligibility criteria for this review question are provided in Table 7.

Table 7-High Frequency ED Attendance SPIDER Framework

SPIDER Framework	Description	Search Terms
Sample	Patients who frequently attend ED (definition of high frequency ED use was not limited) Sample population was not limited to the UK and could include any ages between 0-21.	"Child*" OR "Young people" OR "Paediatric*" OR "Pediatric" OR "Baby"
Phenomenon of **I**nterest	High/frequent use of ED.	"frequen* attend*" OR "frequen* us*" OR "high utili*" OR "super utili*"("accident and emergency" OR "accident & emergency" OR emergency service? OR "casualty" OR "casualty ward" OR "ER" OR (emergency adj2 (care OR healthcare OR department? OR unit OR units OR room? OR treatment?)))
Design	Cohort studies using secondary data.	(cohort adj (study or studies)).ab,ti. OR (observ$ adj3 (study or studies)).ab,ti.
Evaluation	Evaluation factors and variables of interest include definitions of paediatric and young high frequency ED attenders, proportion of ED attenders who are high frequency ED users and paediatric and young high frequency ED user characteristics. Patient characteristics such as sex, socioeconomic status and specific underlying health conditions.	Checked via screening
Research Type	Quantitative.	(cohort adj (study or studies)).ab,ti. OR (observ$ adj3 (study or studies)).ab,ti.

4.3.4 Search Terms

For this systematic review of children and young high frequency ED attenders, a set of search terms were decided and adapted for Medline via Ovid and CINAHL via Ebsco (as terms needed to be manipulated for each platform due to differing Boolean operators and notation). Since this systematic review was chosen to include publications outside the UK, alternative search terms were required to account for differences in medical jargon and general spelling. For example, in countries such as the USA, papers are more likely to use terms such as an 'emergency room' (ER) rather than an 'emergency department' (ED) and authors are more likely to spell 'paediatric' as 'pediatric'. These alternative terms were derived after discussions with medical experts, searching relevant publications and exploring online medical dictionaries. The derived list of search terms for this review question is provided in Table 8.

Table 8-High Frequency ED Attenders Search Terms

Medline via Ovid terms
"frequen* attend*" OR "frequen* us*" OR "high utili*" OR "super utili*"
AND ("accident and emergency" OR "accident & emergency" OR emergency service? OR "casualty" OR "casualty ward" OR "ER" OR (emergency adj2 (care OR healthcare OR department? OR unit OR units OR room? OR treatment?)))
AND "Child*" OR "Young people" OR "Paediatric*" OR "Pediatric" OR "Baby"
CINAHL via Ebsco search terms
((frequen* or high or super or recurrent or regular) N0 (use* or utilis* or utilize* or attend*))
AND (Emergency N0 (department or room or medicine)) OR (Casualty department or (accident N1 emergency))
AND (child* or pediatric or paediatric or adolescent or infant or "young person")

4.3.5 Study Selection

After the above search string was conducted in Medline (using the Ovid interface), Embase and CINAHL (using the EBSCO interface), the corresponding publications were transferred to Endnote to allow for paper screening. The screening process included the exclusion of papers based on the relevancy of the title, abstract and then full text. This was conducted by one person, with queries checked with the broader supervision team. Although the initial search in both Ovid and Ebsco was limited to English language publications, some papers only provided English abstract translations meaning full texts were still in a non-English language. These, alongside publications where full papers were not accessible (after using Endnote links, supervisor access or university library support teams) were also omitted from the final selection (see prisma diagram, Figure 3).

4.3.6 Study Quality Assessment and Risk of Bias

A critical appraisal tool was used to assess the quality of the included studies. Since the publications were selected to only include observational cohort-based studies in this review, the tool was chosen to be the "NIH Quality Assessment tool for Observational Cohort and Cross-Sectional studies". This consisted of fifteen questions alongside question guidance. Each question was answered with either a 'Yes (Y)', 'No (N)', 'Not reported (NR)' or 'Not Applicable (NA)'. To provide a definitive answer as to the quality of the study if the study produced:

- 0-4 'Yes' answers out of the 15 questions the study was rated as poor.
- 5-10 'Yes' answers out of the 15 questions the study was rated as fair.
- 11-15 'Yes' answers out of the 15 questions the study was rated as good.

If a publication was defined as poor using the study quality assessment tool, it would be omitted from the systematic review. Studies defined as poor had a high likelihood of bias within the paper, whereas fair and good studies were less likely to contain high levels of bias.

4.3.7 Data Extraction

For the data extraction procedure in this systematic review, Microsoft Excel was used, and an extraction document was produced. This document consisted of the following extracted information: Author, publication year, study site, setting of data, data collection method, country/area of data origin and main paper objectives, children and young high frequency ED attender sample size, children and young high frequency ED user definition, sample age group, the existence of chronic conditions, children and young high frequency ED attendance as a percentage of total attendance and proportion of children and young ED attenders who are high frequency attenders.

4.4 Results

The search strategy produced a total of 1934 publications for this high frequency ED attendance systematic review. Of these, 30 were deemed relevant after initially screening the abstract. 1 publication had no available full English language paper[3] to screen and 6 were deemed irrelevant. These publications were omitted from the final selection of publications. Hence after full papers were screened, 23 publications were included and could be assessed using the NIH quality assessment tool (see Figure 3). All 23 papers passed the check, ensuring the risk of bias was likely to be low. A total of 17 papers were deemed good, 6 fair and 0 poor (see Table 9). These 23 papers were then analysed, and relevant data extracted.

4.4.1 Characteristics of Included Studies

Of the final selection of 23 studies, there was variation between a number of study characteristics such as the year of publication, country (and city/state) of origin and the children and young high frequency ED attender sample size (see Table 10).

[3] If publications could not be accessed via links and DOIs provided by the search platforms or through university credentials, the university library and/or authors were contacted. Publications were then omitted if full English papers could not be retrieved.

Table 9-NIH Quality Assessment Check Frequent Attenders

NIH Quality Assessment Check

Y, yes; N, no; *CD, cannot determine; NA, not applicable; NR, not reported

	Was the research question or objective in this paper clearly stated?	Was the study population clearly specified and defined?	Was the participation rate of eligible persons at least 50%?	Were all the subjects selected or recruited from the same or similar populations (including the same time period)?	Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Was a sample size justification, power description, or variance and effect estimates provided?	For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome?	Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Was the exposure(s) assessed more than once over time?	Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Were the outcome assessors blinded to the exposure status of participants?	Was loss to follow-up after baseline 20% or less?	Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Quality
Frequent attenders:																
Blair et al, 2017	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	N	Fair
Castillo EM et al, 2015	Y	Y	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Christensen et al, 2017	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Gibson et al, 2010	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Greenfield et al 2021	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Lynch et al, 2019	N	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Samuels-Kalow et al, 2016	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Seguin et al, 2018	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Supat et al, 2018	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Tiller et al, 2021	Y	N	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Alpern et al, 2014	Y	N	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Macneil et al, 2016	Y	Y	NA	Y	Y	Y	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Neuman et al, 2014	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Kroner et al, 2010	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Cabey et al, 2014	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Kersten et al, 2018	Y	Y	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
McDonnell et al, 2012	Y	Y	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Peltz et al, 2017	Y	Y	NA	Y	Y	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Yamamoto et al, 1995	Y	Y	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	N	Good
Zook et al, 2017	Y	Y	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Fair
Mueller et al, 2016	Y	Y	NA	Y	N	N	Y	Y	NA	Y	NA	Y	NA	NA	Y	Good
Greenfield et al 2021	Systematic review															
Giannouchos et al 2019	Systematic Review															-

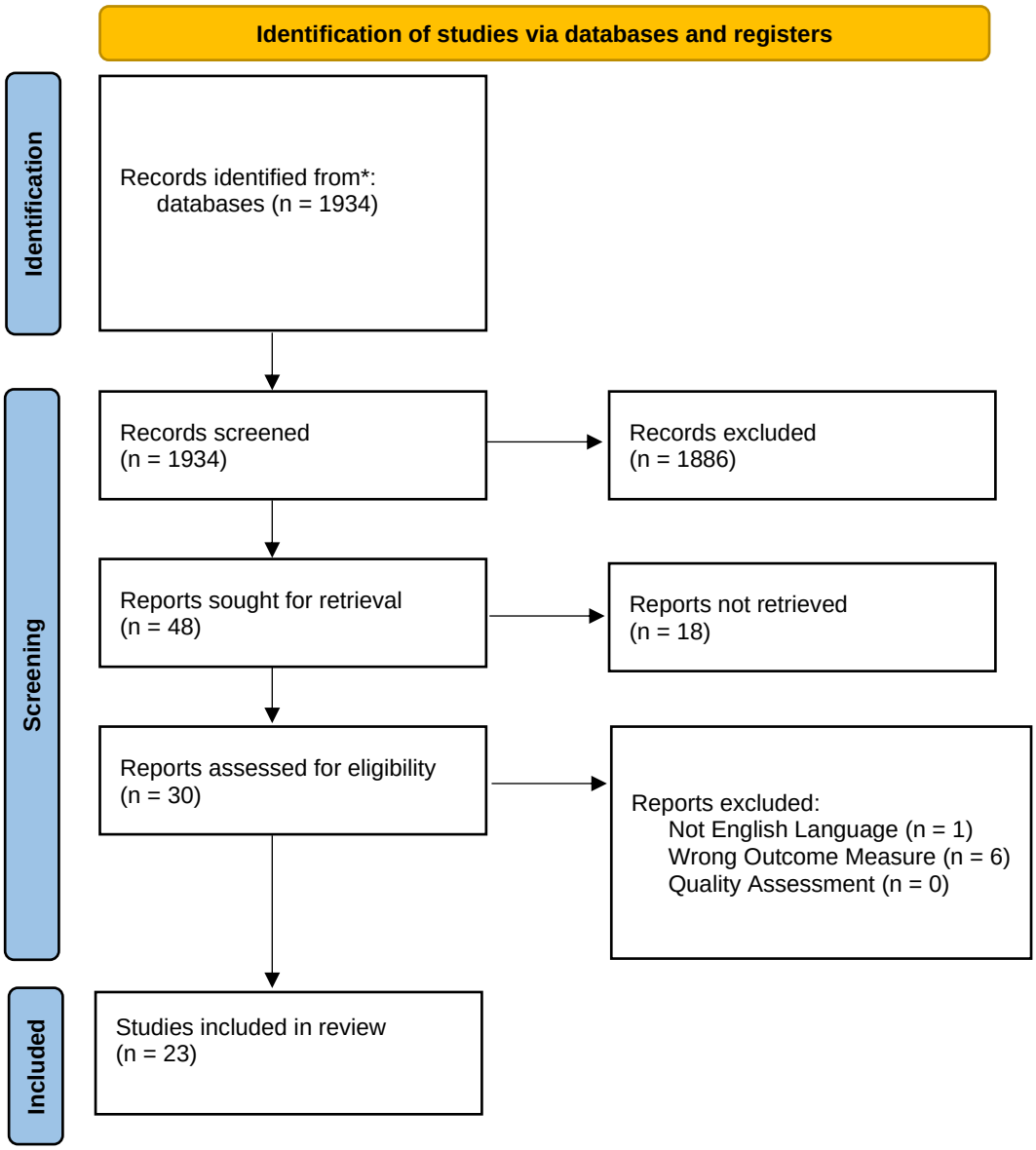

Figure 3-PRISMA Diagram for Frequent Attenders Systematic Review

Table 10-Characteristics of Included Studies

Author	Publication Year	Country	City/state	Sample Size (High Frequency Attenders)	Age groups	Paper objectives
Castillo et al [84]	2015	USA	California	7,147	1-17	Characterising High Frequency ED users
Blair et al [85]	2017	England	Northwest London	655	0-4	Characterising High Frequency ED users
Christensen et al [86]	2017	USA	Minnesota	1,022	0-20	Characterising High Frequency ED users
Giannouchos et al [81]	2019	USA	Nationwide	-	-	Reviewing the literature on paediatric High Frequency ED users to identify and synthesize factors associated with high frequency ED use
Gibson et al [83]	2010	Australia	Perth	4,138	0-15	Characterising High Frequency ED users
Greenfield et al [87]	2021	England	Nationwide	210,102	0-15	Characterising High Frequency ED users
Lynch et al [88]	2019	USA	Florida	581	0-18	Characterising High Frequency ED users
Samuels-Kalow et al [89]	2016	USA	Philadelphia	590	0-21	Characterising High Frequency ED users
Seguin et al [90]	2018	Canada	Montreal	2,474	0-18	Characterising High Frequency ED users
Supat et al [91]	2018	USA	California	15,562	1-17	Characterising High Frequency ED users
Tiller et al [21]	2021	Canada	Alberta/Ontario	121,104	0-18	Characterising High Frequency ED users
Alpern et al [92]	2014	USA	-	24,551	0-17	Characterising High Frequency ED users
Macneil et al [93]	2016	USA	North Carolina	1,343	0-3	Follow High Frequency ED patients to determine if they had a higher likelihood of reported maltreatment.
Neuman et al [94]	2014	USA	Nationwide	153,206	0-18	Characterising High Frequency ED users
Kersten et al [95]	2018	USA	California	3,799	0-18	Is Child Opportunity Index associated with High Frequency ED use
Peltz et al [96]	2017	USA	-	39,945	1-16	Characterising High Frequency ED users
Zook et al [97]	2017	USA	Minnesota & South Dakota	1,006	0-17	Differences in ED use by Native American children
Yamamoto et al [98]	1995	USA	Hawaii	357	0-21	Characterising High Frequency ED users
McDonnell et al [99]	2012	USA	Utah	2,024	0-18	Comparing ED use by insured and uninsured children

Kroner et al [100]	2010	USA	Nationwide	8,823	0-18	Determining whether an ED reliance measure could differentiate between High Frequency ED users
Cabey et al [101]	2014	USA	North Carolina	16,664	0-3	Characterising High Frequency ED users
Mueller et al [102]	2016	USA	Nationwide	17,943	0-19	Characterising High Frequency ED users
Greenfield et al [103]	2021	Global	-	-	0-21	Systematic review characterising High Frequency ED users

The included publications spanned 26 years ranging from 1995 to 2021. The majority of studies were published within North America (USA [81, 84, 86, 88, 89, 91-102] and Canada [21, 90]), with only three publications analysing data collected outside this region (UK [85 87] and Australia [83]). The sample of children and young high frequency ED attenders analysed in studies ranged from 357 [98] to 210,102 [87] individuals. The most common age group considered in studies was individuals aged 0-18. Three studies also specifically analysed high frequency ED users under the age of 3 [93, 101] and 4 [85] respectively. Some publications extended their analysis to include information regarding young adults, with four studies allowing patients to be under the age of 21 [89, 98], 20 [86] and 19 [102] respectively. The main objective of the majority of included publications was to characterise high frequency ED attenders [21, 83-92, 94, 96, 98, 101, 102]. Additionally, five studies explored predictors of high frequency ED attendance including factors such as: child opportunity indices [95], medical insurance status [99], deprivation status [87] and ethnic background [87, 97]. Two systematic reviews were also returned from the search and had the main objective of synthesising characteristics of paediatric high frequency ED users, one of which considering publications specifically within the United States.[81]

4.4.2 Characterising Children and Young High frequency ED Attenders

The factors associated with children and young high frequency ED attenders were provided in all 23 studies. Commonly reported characteristics included: the proportion of total ED visits high frequency ED attenders make, the proportion of ED users that are defined as high frequency ED users, the age of high frequency attenders and proportion of high frequency ED users living with chronic conditions. These characteristics are summarised in Table 11.

Table 11-Characteristics of High Frequency Users

Author	High Frequency attender yearly threshold	% of total visits			% of High Frequency ED users			Most common High Frequency ED users age group	% with chronic conditions
		n/N	%	95% CI	n/N	%	95% CI		
Castillo et al [84]	6	54,038/1,039,557	5.2	[5.16%, 5.24%]	7,147/704,585	1	[0.99%, 1.04%]	-	-
Blair et al [85]	4	3,337/16,603	20.1	[19.49%, 20.72%]	655/10,169	6.4	[5.97% ,6.94%]	-	23%
Christensen et al [86]	4	6,902/16,317	42.3	[41.54%, 43.06%]	1,192/15,650	8	[7.21%, 8.04%]	-	41.7%
Gibson et al [83]	5	-	-		6,897/378,068	1.8	[1.78%, 1.87%]	28 day- 4 years (65%)	-
Greenfield et al [87]	4	-	-	-	210,102/2,308,816	9.1	[9.06%, 9.14%]	0-4 (33.4%)	-
Lynch et al [88]	4	-	-		581/13,009	4.47	[4.12%, 4.84%]	15-18 (53.4%)	-
Samuels-Kalow et al [89]	4	-	-		590/61,430	1	[0.88%, 1.04%]	0-4 (41.8%)	-
Seguin et al [90]	5	15,612/94,155	16.6	[16.34%, 16.82%]	2,474/52,088	4.7	[4.57%, 4.94%]	1 (median)	-
Supat et al [91]	6	115,158/1,238,262	9.3	[9.25%, 9.35%]	15,873/690,130	2.3	[2.26%, 2.34%]	-	-
Tiller et al [21]	3*	-	-	-	-	-		28 day- 4 years (49.8%)	-
Alpern et al [92]	4	-	-		27,807/695,188	4	[3.95%, 4.05%]	0-4 (49%)	40%
Macneil et al [93]	5	-	-	-	-	-		-	35.5%
Neuman et al [94]	4	815,833/3,263,330	24	[24.95%, 25.05%]	153,206/1,896,547	8	[8.04%, 8.12%]	0-4 (67.6%)	54.4%
Kersten et al [95]	4	-	-	-	3,799/47,175	8	[7.81%, 8.3%]	-	-
Peltz et al [96]	4	-	25		39,945/469,941	8.5	[8.42%, 8.58%]	-	16.5%

Zook et al [97]	4	6,030/52,797	11.4	[1.71%, 1.98%]	722/39,220	2.1	[1.71%, 1.98%]	<1	-
Yamamoto et al [98]	10 over 4.6 years	-	-	-	-	-		0-4	74%
McDonnell et al [99]	5	-	-	-	100/2,001	5	[4.08%, 6.05%]	-	-
Kroner et al [100]	2	-	-	-	8,823/84,029	10.5	[10.29%, 10.71%]	-	-
Cabey et al [101]	5*	-	-	-	2,333/16,664	14	[13.48%,14.54%]	-	-
Mueller et al [102]	4*	15,527/26,770	58	[57.41%, 58.59%]	2,631/5551 (cancer patients)	47.4	[46.08%,48.72%]	0-4	-

* Minimum threshold for studies using centile use definition

4.4.2.1 Children and Young High Frequency ED User Definition

The majority of studies produced a numeric threshold definition of yearly ED attendances at which patients would be classified as a high frequency ED user.[83-97, 99, 100] This figure ranged from 2-6 ED attendances per year, with a modal threshold of 4 ED attendances per year. Three publications provided a percentile definition of a high frequency ED user. For these studies, a high frequency ED user was defined as the top 10% users of EDs.[21, 101, 102]

4.4.2.2 Use of EDs by Children and Young High Frequency ED Attenders

Children and young high frequency ED attenders made up a relatively small proportion of all children and young ED users. As shown in the forest plot, although the studies used a variety of ED attendance thresholds to define high frequency ED attenders, some homogeneity was found when considering the proportion of total C&YP high frequency ED users (see Figure 4). A total proportion of 7.7% of paediatric and young ED attenders were reported as high frequency attenders when combining studies using a high frequency attender threshold of 4 ED attendances made in a year [85-89, 94-97]. High frequency ED attenders were responsible for 5% [98] to 42.3% [86] of all ED attendances over the respective study period with a total fixed proportion of 24.9% across publications using a high frequency user definition of 4 ED attendances made in a year (see Figure 5)

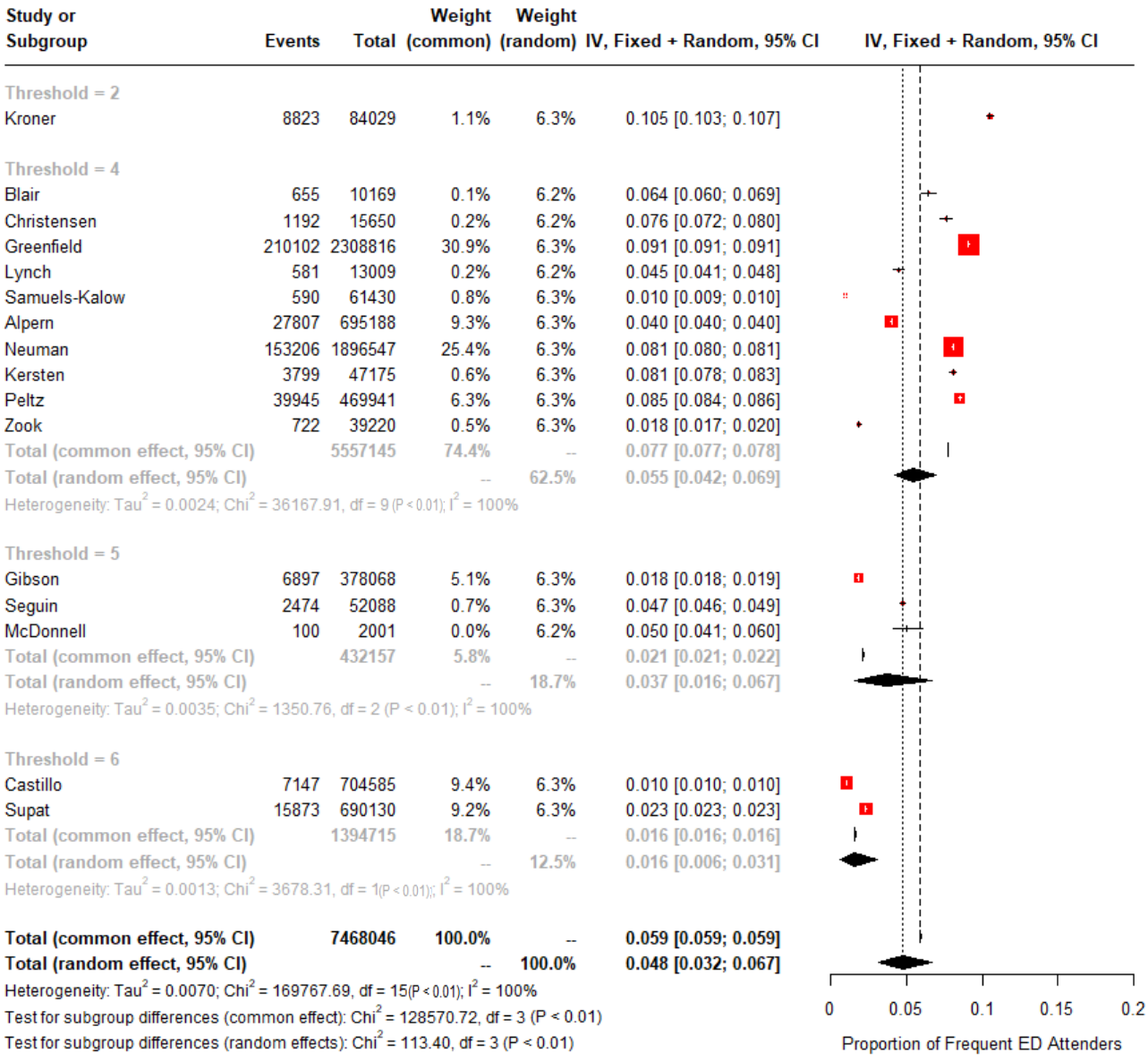

Figure 4-Forest Plot to Show the Proportion of Frequent ED Attenders

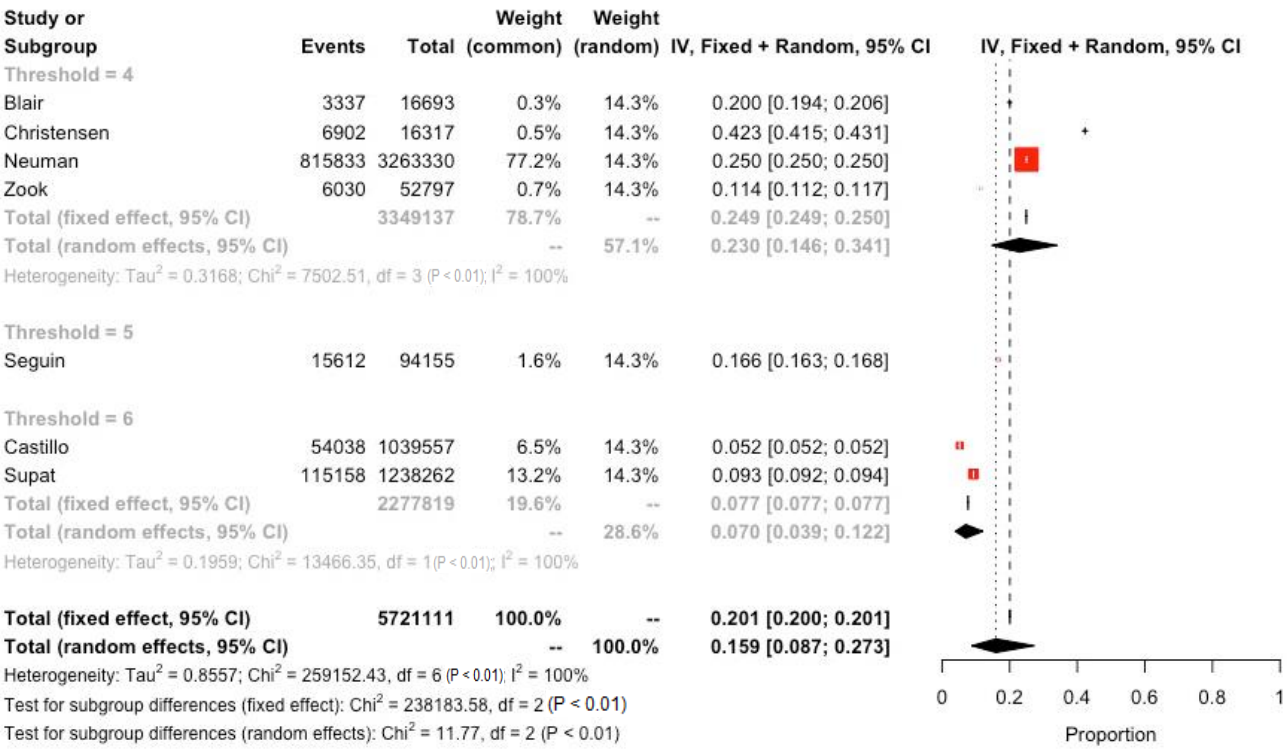

Figure 5-Forest Plot to Show the Proportion of ED Attendances Frequent Attenders Make

4.4.2.3 Age Demographics of Children and Young High Frequency ED Users

Studies exploring predictors of high frequency ED attendance categorised patients into specific age brackets. These age brackets differed across studies due to the heterogeneity of age demographics considered in publications, and author discretion. This being said, 10 publications found that high frequency ED attenders were most likely be under the age of four [21, 83, 87, 89, 90, 92, 94, 97, 98, 102], with three of these studies further suggesting that paediatric and young high frequency ED users were most likely to be infants under the age of one.[87, 90, 97]

4.4.2.4 Prevalence of Chronic Conditions in High Frequency ED Attenders

The prevalence of chronic conditions in high frequency ED users was reported by a number of publications. These studies found that 16.5% [96] to 74% [98] of high frequency ED attenders had one or more pre-diagnosed chronic conditions prior to their ED attendance. It was also reported that high frequency attenders were more likely to have chronic pulmonary disease (OR=6.1, 95% CI=5.8, 6.4) or a previous psychiatric diagnosis (OR=5.8, 95% CI=5.3, 6.4) in comparison to occasional users.[84] In addition to this, one study reported that all extreme high frequency ED attenders (those who made more than twenty ED visits per year) suffered from a serious chronic illness.[83]

4.4.3 Other Systematic Literature Reviews Returned

Two systematic reviews were returned from the search for relevant literature. Both reviews explored characteristics of high frequency ED attendance of individuals under the age of

twenty-one. One review only considered publications produced within the USA, whereas the newest review did not limit the geographical location of publications.

4.4.3.1 Giannouchos et al

The objective of this review was to identify and synthesise characteristics and factors associated with high frequency ED attendance among children within the United States.[81] The published systematic review included 15 studies, 13 of which were also included in this systematic review. The 2 studies that were not included in our review were due to differing inclusion criteria (as the previously published systematic review included studies that solely collected primary data). As the majority of publications included in the published systematic review were also included in our review, results were very similar, with the only exception being the inclusion of insurance status. Since the published systematic review focused solely on US based studies, an association between public insurance compared to private residency and ED attendance was specifically picked up on. Although this may not have been mentioned in the non-US based publications due to the discrepancy of healthcare systems in various countries, this result may provide evidence to suggest that factors such as deprivation may also be a predictor of high frequency ED attendance in C&YP.

4.4.3.2 Greenfield et al

A further systematic review describing characteristics of high frequency ED attendance was published in 2021 and was therefore produced after the systematic review conducted in this PhD (2020). Similar to our systematic review, the published review did not limit the papers to a specific country and considered children and young individuals under the age of 21. The published systematic review synthesised results such as: definitions and rates of high frequency ED attenders, characteristics of frequently attending children, health insurance

factors and clinical factors. The review also concluded that frequently attending children were more likely to be less than 5 years old and have long term conditions, to be high frequency users of primary care services and were commonly diagnosed with upper respiratory tract infections, viral infections and gastroenteritis in the ED.

4.4.4 Updating Literature Review Search

As this systematic review was completed in 2022, we re-ran the review search terms to include any relevant recently published studies. This produced no new publications.

4.5 Discussion

4.5.1 Summary of Main Findings

For this high frequency ED attender review, 23 publications were analysed, with the majority providing a main objective of describing and/or characterising individuals who classified as high frequency ED attenders. Although the majority of studies used a yearly attendance threshold when defining high frequency ED attenders, this threshold ranged from 2-6 attendances (with a modal threshold of 4 across studies). Publications found that although paediatric and young high frequency ED attenders make up a relatively small number of ED attenders, they account for a proportionally large number of the total ED attendances. Paediatric and young high frequency ED attenders are more likely to be younger children and have a chronic condition with a reported modal prevalence of 35.5%. A nationwide study produced in the UK found that ethnicity and deprivation were associated with high frequency attendance.

4.5.2 Strengths and Limitations

This systematic review included a number of publications exploring high frequency ED attendance across a variety of different countries. This has shown that high frequency ED attenders have common characteristics irrespective of the healthcare system they were treated in. As the definition of a high frequency ED attender varied across publications, meta-analyses of commonly reported characteristics were not possible. If a widely used definition of a high frequency ED attender existed, statistical techniques could be implemented to compare and aggregate previously published results. Although the I-squared value was presented in the forest plots, a number of limitations exist regarding the measure. This

includes the fact that it depends on sample size, outcome type (e.g. binary) and outcome rate, and is not strictly a measure of heterogeneity. While data was only formally extracted by one person, the searches and search outputs were discussed in detail during supervision and quantitative data extracted was reviewed by a supervisor for consistency and checking in the case of unexpected findings. Although exclusion criteria was used when searching for literature in this review, only the inclusion criteria was explicitly listed. As this systematic review excluded non-peer reviewed literature, grey literature including evaluation reports are likely to have been missed.

4.5.3 Relationship with Other Research

In addition to high frequency use of secondary healthcare services (such as EDs) by C&YP, previously published literature has also explored high frequency use of primary healthcare services. A systematic review published in 2020 explored sociodemographic and clinical characteristics of children who attended primary care services frequently.[104] A high frequency attender of primary care services was defined as a child who attends a primary care service 4 or more times in a year. Similar to high frequency ED attendance, high frequency attendance of primary care services was associated with younger age and the presence of chronic conditions. On the other hand, factors such as higher school absences, high levels of parental anxiety and the presence of psychosocial and mental health problems were found to be associated with high frequency primary care use but not considered for high frequency ED use in our review.

4.5.4 Implications for Practice, Policy and Research

Although high frequency ED attenders represent a relatively small proportion of paediatric and young ED attenders, these patients make a large proportion of total ED visits. This result

was found in all papers providing this information, irrespective of geographical location, age groups considered or paediatric and young high frequency ED attender definitions. In addition to this, despite studies providing a variety of high frequency ED attender characteristics, further information such as ED outcomes, and access to other healthcare services (such as primary care services) may also provide useful insights into ways in which paediatric and young ED attenders can be managed more effectively.

4.5.5 Conclusions

This systematic literature review has indicated that paediatric and young high frequency ED users possess a number of common characteristics irrespective of the country in which ED use was analysed. Health systems should address the needs of high frequency ED users who may have underlying chronic or complex conditions by expanding the provision of healthcare available to these patients, to ensure they are efficiently treated in an appropriate setting. Although a small proportion of paediatric and young high frequency ED attenders may make choices regarding their healthcare decisions, the majority of these patients will be attending UEC services due to choices made by parents and caregivers. Healthcare systems should therefore focus their attention on educating and assisting parents and caregivers when determining the most appropriate healthcare services when their child requires medical treatment.

4.6 Chapter Summary and Evidence Gaps

This literature review outlined the difficulty in comparing characteristics and predictors of high frequency ED attendance due to a variety of definitions being implemented. This provides the opportunity for this PhD to assess methods of analysing factors associated with

high frequency attendance without taking this dichotomous approach. As the UK has a unified, free-to-access healthcare system, an individual's medical insurance status is unlikely to be useful when describing and characterising high frequency ED attenders in the UK. As shown in the study conducted in the UK, an index of multiple deprivation status measure can be used to explore the association between deprivation and high frequency ED use in this PhD. This study suggested that region specific studies could explore the association between factors such as deprivation and ethnicity in detail using more granular data. This may include information regarding reasons for attendance, ED outcomes and high frequency attendance over multiple years.

5 Methodology

5.1 Chapter Outline

The previous chapters helped focus the primary research objectives of this PhD. To address these research objectives, it was decided that a large database of routine patient data would be analysed. This quantitative approach was chosen to ensure a large sample size could be utilised in the planned analyses. This methodology section outlines how health data (in particular EHRs) can be used by both healthcare professionals and researchers. It then describes the strengths and limitations of using this data for research in the context of this PhD. This section then outlines how this PhD analysed the CUREd research database using the statistical package R and states the precautionary steps taken when handling sensitive patient data. This section ends by providing a summary of the statistical methods used to address the research objectives in this PhD.

5.2 Health Data

Health data includes any data related to health conditions, reproductive outcomes, cause of death and quality of life for an individual or population.[105] This data can include a wide variety of information such as clinical, environmental, socioeconomic and behavioural metrics associated with health and wellbeing.[106] Health-related data collected by healthcare providers has increased significantly and has subsequently led to advancements in health information technology.[107] These advancements have contributed to the worldwide adoption of electronic medical health records, with the quantity of electronic data produced within healthcare services growing exponentially in recent years.[108] Although the growth of EHR data has caused a number of ethical dilemmas (such as patient consent to data sharing), the

detail included in these records has led to developments in a variety of previously unexplored areas within healthcare research.[109]

5.2.1 Electronic Health Record Data

EHRs are any digital document or system that contains information regarding an individual's health.[110] In 2005 the NHS began the deployment of EHR systems within NHS Trusts and aimed for all patients to have a centralised EHR by 2010.[111] Within the UK the vast majority of hospitals, trusts and medical organisations have already switched to EHRs due to a recent push by NHS England, expecting that all healthcare services meet a level of core digitalisation by 2024.[112]

5.2.1.1 Benefits of Electronic Health Records

5.2.1.1.1 Healthcare Settings

The implementation of EHRs within the healthcare setting has a number of advantages to patients, healthcare professionals and the healthcare system in general. At the point of care, healthcare professionals can quickly obtain accurate, up-to-date and complete information about their patients using EHRs. This ensures that medical professionals can diagnose patients more effectively, thus reducing the likelihood of medical errors. EHRs have also enabled more reliable prescribing which has led to safer care for patients presenting at healthcare services.[113]

5.2.1.1.2 Healthcare Research

In addition to EHRs providing assistance in clinical decision making, they can also be advantageous in healthcare research. EHRs generally contain a variety of useful information such as: demographic, geographical, clinical and administrative data. This, coupled with the

fact that extremely large quantities of patient information are gathered and stored, has meant a large number of quantitative studies have taken place using EHRs.[114] When conducting healthcare research using large samples of EHR, studies generally benefit from increased statistical power and validity of analyses. In addition to this, EHRs often allow for datasets to be linked across the healthcare system, which enable novel questions to be explored in a given research area.[115] As primary data collection methods may be expensive and time-consuming, the use of EHRs in healthcare research can often be more cost-effective.

5.2.1.2 Limitations of Electronic Health Records

5.2.1.2.1 Healthcare Settings

Although a number of benefits exist when using EHRs in the healthcare setting, there have been growing concerns about the potential disadvantages associated with this information. These disadvantages include: the high costs of EHR adoption, implementation/ongoing maintenance, overdependence on technology, and risk of patient privacy violations.[109] There have also been concerns raised in relation to inappropriate access of EHRs by medical professionals within healthcare settings. These patient-privacy concerns have arisen as a result of numerous real-life examples, thus outlining the importance of information security. This being said, due to the relative ease at which EHRs can be accessed by medical professionals, steps have been taken by policymakers and organisations to ensure the use of EHRs comply with strict laws intended to maintain patient privacy of clinical and personal information.

5.2.2 Information Governance and Healthcare Data Research

5.2.2.1 Principles and Relevant Legislation

Due to the sensitive nature of information included within healthcare data, a number of key principles and legal requirements exist when accessing this data. In particular, regulations governing the use of healthcare data in research include: The Health Service (Control of Patient Information) Regulations 2002 and The Data Protection Act 2018.[116] In addition to laws underpinning research associated with healthcare data, there are also guidelines set out by the Health Research Authority (HRA) designed for the handling of personal information in a robust and transparent manner. To ensure high ethical and quality standards are maintained by individuals or organisations who have access to healthcare data, the HRA have stated that holding, obtaining, recording, using and sharing information must be conducted in an appropriate manner.[110] According to the HRA, the individual or organisation must therefore strike an appropriate balance between openness and confidentiality in the management and use of information, fully acknowledge its public accountability (but equally place an importance on the confidentiality of personal information), and recognise the need to share information with other organisations in a controlled manner consistent with the interests of research.[110] To ensure the above principles and legislation are followed by individuals conducting healthcare research within the University of Sheffield, students and staff members are required to partake in a number of modules and training courses.

5.2.2.2 Personal Preparation and Training

Before data is presented to a research student or staff member within the University of Sheffield, a number of training modules must first be passed. The first course is designed to prepare researchers with the skills related to information security and includes sections on protection of personal and research data, information governance and cyber safety. In

addition to this, a mandatory module in research ethics and integrity must also be passed. This module provides information regarding ethics of research involving humans, health and social care research and data integrity.

5.2.2.3 Accessing the CUREd Database

The CUREd research database is stored on a University of Sheffield research data server with restricted access and is frequently backed-up. CUREd data is accessed using a Virtual Machine (VM) connected using an encrypted university provided laptop via a Virtual Private Network (VPN). In addition to these measures, a data governance course was completed to ensure essential data confidentiality principles are met. In particular, a main principle stated that no data shall be removed from the VM unless information is being summarised in a figure or table (in which case patient IDs must remain anonymous).

5.2.2.4 Data Linkage for Data Provided in the CUREd Database

The CUREd database uses a combination of deterministic and probabilistic record linkage techniques. For ED attendances, admitted patient care episodes and NHS 111 calls a large proportion of valid NHS numbers were recorded (98%, 99.7% and 96.3% respectively). Hence a deterministic entity resolution was implemented to identify all records amongst the datasets that correspond to the same individual. This process is outlined below:

- **Step 1**: Assign each distinct pair (valid NHS number, valid date of birth, a distinct CUREd identifier (CUREd ID)
- **Step 2**: Attempt to link records with valid NHS numbers but no valid date of birth to a CUREd ID based on approximate birth year (calculated from activity date and age at activity)

- **Step 3:** Attempt to link remaining records to an assigned CUREd ID by provider code, provider patient ID, and date of birth matches (provided this matches only 1 CUREd ID)
- **Step 4:** Attempt to link remaining records to an assigned CUREd ID by first name, last name, sex, date of birth, and postcode matches (provided this matches only 1 CUREd ID)
- **Step 5:** Attempt to link remaining records to an assigned CUREd ID by sex, date of birth, and postcode matches (provided this matches only 1 CUREd ID)
- **Step 6**: Cluster remaining records by agreement on any of the following patterns:

1. Provider code, provider patient ID, and date of birth matches
2. First name, last name, sex, date of birth, and postcode
3. Sex, date of birth, and postcode matches and assign each distinct cluster to a new CUREd ID

- **Step 7:** Assign each remaining record to its own CUREd ID

1. Ambulance records excluded as no provider patient ID was available
2. NHS 111 helpline records were excluded as names were not available
3. We excluded 1% of postcodes with greatest number of distinct patients registered at such postcodes. These likely represent communal establishments, such as prisons.
4. Ambulance records excluded as recorded postcodes related to incident locations rather than place of residence.

As a valid NHS number was recorded only for 14.4% of ambulance incidents a further probabilistic linkage step was required. This included obtaining NHS numbers for ambulance incidents resulting in conveyance to a hospital (60.1%). The CUREd dataset team then identified duplicates by detecting records that had the same patient, start/finish date-times and

clinical information. The match weight threshold was chosen to the 99.9% specificity limit – this corresponded to a sensitivity of 98.1%.

5.2.2.5 NHS 111 Calls Dataset

This dataset consists of all calls made to the NHS 111 telephone service operated by the Yorkshire Ambulance Service NHS Trust. The majority of data included in this dataset comprises items mandated by NHS England's NHS 111 Minimum Dataset and recorded by the Trust's systems. In this dataset, data is available from April 2013 to March 2017 and includes information regarding 4,789,273 distinct NHS 111 calls. Data provided in the NHS 111 dataset are categorised into: Patient, System, Call, Organisation, Practitioner and Geographical data. Examples of specific variables included in the data categories are given below:

Table 12-Description of NHS 111 Call Dataset

Data Category	Description
Patient Data	Individual demographic information including sex, ethnicity and age information.
System Data	Information such as record linkage methods, provider code of submitting organisation and NHS number status indicators (amongst other indicators).
Call Data	Information regarding the call made to NHS 111 and includes: date and time of calls, call handler skill set, call dispositions and patient symptoms.
Organisation Data	Information for the provider code of NHS 111 service.
Practitioner Data	Information related to the GP practice code (including pseudonymised code).
Geographical Data	Information regarding deprivation indices, including Index of Multiple Deprivation data (for income, employment, education, health, crime, housing and environment measures).

5.2.2.6 Ambulance Incidents Dataset

The Ambulance incidents dataset contains emergency call records to the 999-ambulance service operated by The Yorkshire Ambulance Service NHS Trust, with data being recorded by the Trust's systems. For this dataset, data is available from April 2012 to March 2017 and comprises 4,382,835 distinct ambulance incidents. Data provided in the Ambulance incidents

dataset are categorised into: Patient, System, Call, Organisation, Resource and Geographical data. Examples of specific variables included in the data categories are provided below:

Table 13-Description of Ambulance Incidents Dataset

Data Category	Description
Patient Data	Individual demographic information including sex, ethnicity and age information.
System Data	Information such as record linkage methods, provider code of submitting organisation and NHS number status indicators (amongst other indicators).
Call Data	Information regarding the call made to 999 and includes date and time of calls, urgency levels, source of call and patient symptoms.
Organisation Data	Information for the organisation providing treatment and advice.
Resource Data	Information regarding the arrival time to, and departure time from the scene and stood down time.
Geographical Data	Information regarding deprivation indices, including Index of Multiple Deprivation data (for income, employment, education, health, crime, housing and environment measures).

5.2.2.7 Emergency Department Attendance Dataset

The ED attendance dataset consists of patient records for activity at participating Hospital Trusts' EDs, Urgent Care Centres and Walk-in-centres. The data included in this dataset mainly comprises items mandated by the national Commissioning Data Set (CDS). This data was generated by the patient administration system(s) within each corresponding Trust. In particular, the ED attendance dataset contains data collected from April 2013 to March 2017 and provides information regarding 9,787,270 distinct attendances. Data provided in this dataset are categorised into: Patient, System, Clinical, Attendance, Organisation, Practitioner and Geographical data. Examples of specific variables included in the data categories are provided below:

Table 14-Description of ED Dataset

Data Category	Description
Patient Data	Individual demographic information including sex, ethnicity and age information.
System Data	Information such as record linkage methods, provider code of submitting organisation and NHS number status indicators (amongst other indicators).
Clinical Data	Information such as primary and secondary diagnosis and procedures, low acuity attendance indicator and frailty risk scores.

Attendance Data	Information such as arrival mode, attendance category and disposal, incident location type, patient group, source of referral, department type and arrival date/time.
Organisation Data	Information for the organisation providing treatment and advice.
Practitioner Data	Information related to the GP practice code (including pseudonymised code).
Geographical Data	Information regarding deprivation indices, including Index of Multiple Deprivation data (for income, employment, education, health, crime, housing and environment measures).

5.2.3 Data Preparation and Checking

A large quantity of data obtained through the CUREd research database was analysed in this PhD. The data extraction, cleaning, preparation, linking and statistical analyses were performed using R 4.2.1 (R Software Foundation). Data cleaning is the process of transforming raw-data into consistent-data, ready to be analysed using a variety of methods. This was achieved in this PhD by ensuring duplicate or irrelevant observations were removed, structural errors were rectified and obvious outliers were filtered.[117]

Data preparation included checking the class and dimensions of the data to ensure the variables included in each class were classified correctly. For example, when data was initially imported into R-Studio, variables that were binary in nature were often defined as continuous by the statistical package and were therefore corrected. In addition to checking the class and dimension of the data, functions provided in R-Studio allow data-fields to be assessed for missing values. Missing values were then addressed by either omitting them, or by conducting extrapolation methods using other saturated data.

5.2.3.1 Data Visualisation

In the majority of the analyses conducted during this PhD data was routinely visualised in the form of graphs and tables. Data manipulation and visualisation packages such as “dplyr” and “ggplot” were accessed within R-Studio to produce high quality plots of the data (including histograms, boxplots and scatter-graphs). These plots provided information regarding the distribution of the data and meant focused analyses could take place. For example, as a

bimodal distribution was found when plotting the time taken to attend ED following an NHS 111 call, this helped determine how the data should be modelled (a bimodal lognormal mixture distribution).

5.2.3.2 Test Dataset

To ensure computational methods were appropriately applied to data contained in the CUREd datasets, a sample of the full data was provided (via the use of a Virtual Machine). This test dataset was analysed to test computational methods proposed for the analysis of the PhD research questions. In particular, since the test dataset was a subset of the full CUREd dataset, although the quantity of data was reduced, the variables included were identical. Hence, R scripts were produced and tested using this smaller dataset and run using the full data when it was deemed appropriate.

5.3 Statistical Approaches

A number of statistical approaches were implemented to address the research objectives in each of the four studies conducted in this PhD. These statistical approaches and methods are examined in this section.

5.3.1 Generalised Linear Models

A number of generalised linear models (GLMs) were used in this PhD to test the association between a response (dependent) variable, and a number of explanatory (independent) variables. A GLM[118] models the expected value of a response variable y conditional on p explanatory variables $\boldsymbol{x} = (x_1, x_2, \dots, x_p)^{\boldsymbol{T}}$.

The GLM consists of three elements:

- The assumption that a response variable y follows a probability distribution belonging to the exponential family of distributions. The distribution of y is assumed to be a member of the exponential family if its probability density/mass function can be written in the following form:

$$f(y;\theta,\varphi) = \exp\left(\frac{y\theta - b(\theta)}{a(\varphi)} + c(y,\varphi)\right)$$

- A linear predictor η of the p explanatory variables given by:

$$\eta = \beta_0 + \beta_1 x_1 + \beta_2 x_x + \cdots + \beta_p x_p$$

  Where $\boldsymbol{\beta} = (\beta_0, \beta_1, \beta_2, \dots, \beta_p)^{\boldsymbol{T}}$ are to be estimated.

- The existence of a link function $g(.)$ such that $E[y|\boldsymbol{x}] = g^{-1}(\eta) + \varepsilon$

  Where ε denotes an independent random error term.

A GLM was used in this PhD to test the association between the number of ED attendances an individual made, and the patient's sex, age, deprivation status and ethnicity. After comparing the fit of a number of count-response GLMs, it was decided that a zero-truncated poisson model provided the best fit to the data. This model assumes the underlying distribution of a response variable y (defined as the number of yearly ED attendances an individual makes) approximately follows a zero-truncated poisson distribution.[119] This model was deemed appropriate, as the response value was greater than or equal to one ($y \geq 1$), as data was available for those making at least one attendance in the year. This model removed the necessity of producing a binary definition for a high frequency attender. Hence the underlying distribution of y is given by:

$$f(y;\lambda) = P(y = k) = \frac{\lambda^k e^{-\lambda}}{k!\,(1 - e^{-\lambda})}, \quad k = 1,2,3,\dots$$

With the following GLM setup:

$$E[y|\boldsymbol{x}] = g^{-1}(\eta) + \varepsilon$$

$$\eta = \beta_0 + \beta_1 x_{Sex} + \beta_2 x_{Age} + \beta_3 x_{Deprivation} + \beta_4 x_{Ethnicity}$$

Where the link function $g(.)$ was chosen to be the log function.

Hence, $\boldsymbol{\beta} = (\beta_0, \beta_1, \beta_2, \beta_3, \beta_4)^{\boldsymbol{T}}$ were estimated to determine the incidence rate ratios (IRR) for each of the explanatory variables (and intercept). This was computed by implementing the iteratively reweighted least squares method to find the maximum likelihood estimations of the above parameters using the "VGAM" package in R.

When determining whether the above patient characteristics were associated with the heterogeneity of reasons for attendance (using a Herfindahl index, see section 9.5.4 for further detail), a standard linear regression model was computed. This assumed an individual's Herfindahl index (y) was approximately normally distributed with the following probability distribution function:

$$f(y; \mu, \sigma) = \frac{1}{\sigma\sqrt{2\pi}} e^{\frac{-(y-\mu)^2}{2\sigma^2}} \qquad y \in \mathbb{R}, \sigma^2 > 0, \mu \in \mathbb{R}$$

With the following GLM setup:

$$E[y|\boldsymbol{x}] = g^{-1}(\eta) + \varepsilon$$

$$\Rightarrow E[y|\boldsymbol{x}] = \beta_0 + \beta_1 x_{Sex} + \beta_2 x_{Age} + \beta_3 x_{Deprivation} + \beta_4 x_{Ethnicity} + \varepsilon$$

As the link function $g(.)$ was chosen to be the identity function.

Hence, $\boldsymbol{\beta} = (\beta_0, \beta_1, \beta_2, \beta_3, \beta_4)^{\boldsymbol{T}}$ were estimated to determine the strength and direction of the association between the heterogeneity of reasons for attendance and the above patient characteristics. This was computed by implementing the ordinary least squares method to find the maximum likelihood estimations of the above parameters using the "stats" package in R.

5.3.2 Generalised Linear Mixed Effects Models

When exploring the association between patient/NHS 111 call characteristics and subsequent low acuity ED attendances, a logistic regression model was computed. As this data included multiple NHS 111 related ED attendances by individuals, a patient level random effect was also included in this model. Hence, the response variable (y) in this model was the binary variable suggesting whether an NHS 111 related ED attendance was defined as low acuity (see section 6.4.7.4 for further details), with the patient's sex, age, deprivation status and whether their NHS 111 call occurred out of hours being explanatory variables. Hence a mixed effects logistic regression model was computed by initially assuming y was a Bernoulli random variable with the following probability mass function:

$$f(y) = p^{y}(1-p)^{(1-y)} \quad y \in \{0,1\}, \;\; p \in [0,1]$$

With the following generalised linear mixed effects setup:

$$E[y|\boldsymbol{x}] = g^{-1}(\eta) + \varepsilon$$

$$\eta = \beta_0 + \beta_1 x_{Sex} + \beta_2 x_{Age} + \beta_3 x_{Deprivation} + \beta_4 x_{Call\ out\ of\ hours} + \gamma_{Patient\ ID}$$

Where the random effect $\gamma_{Patient\ ID} \sim N(0, {\sigma^2}_{Patient\ ID})$

Hence, by using a logit link function $\ln\left(\frac{E[y|\boldsymbol{x}]}{1-E[y|\boldsymbol{x}]}\right)$ we can deduce the log odds of an individual making a low acuity NHS 111 related ED attendance:

$$\ln\left(\frac{E[y|\boldsymbol{x}]}{1-E[y|\boldsymbol{x}]}\right) = \eta$$

Therefore, the odds ratios used in the results of this analysis was given by:

$$\frac{E[y|\boldsymbol{x}]}{1-E[y|\boldsymbol{x}]} = e^{\eta}$$

With $\beta_0, \beta_1, \beta_2, \beta_3, \beta_4, {\sigma^2}_{Patient\ ID}$ estimated by computing a laplace maximum likelihood method using the "GLMM" package in R.

5.3.3 Quantile Regression for Count Data

In addition to the zero-truncated poisson regression model used to explore factors associated with rates of ED attendance in individuals, quantile regression was used to examine this relationship specifically for those attending EDs most often. This enabled us to focus on the factors associated with ED use in individuals belonging in the upper tail of the ED attendance distribution. Unlike linear regression – which models the conditional mean of a response variable $E[y|\boldsymbol{x}]$ in the GLM framework, quantile regression models the expected quantile q of y, $Q_q[y|\boldsymbol{x}]$. Hence for a given quantile q we modelled the number of ED attendances an individual makes in a year. However, like linear regression, quantile regression requires the response variable to be continuous, which is not the case in the ED attendance count data (data is discrete). To combat this, studies have suggested the use of a "jittering" transformation method that combines the addition of a random uniform variable to the discrete response variable y, then producing a log transformation of this new variable. This is outlined below:

$$Z = Y + U, \quad U \sim Unif(0,1)$$

$$T(Z;q) = \begin{cases} \log(Z-q) & if\ Z > q \\ \log(\zeta) & if\ Z \leq q \end{cases},$$

Where ζ is a suitably small positive number introduced to ensure the transformation is feasible for $Z \leq q$, and q is a given quantile. Hence, quantile regression can be computed using this transformed variable:

$$Q_q[T(Z)|\boldsymbol{x}] = \beta_0 + \beta_1 x_{Sex} + \beta_2 x_{Age} + \beta_3 x_{Deprivation} + \beta_4 x_{Ethnicity} + \varepsilon$$

With $\beta_0, \beta_1, \beta_2, \beta_3, \beta_4$ estimated using a quantile regression coefficients modelling (QRCM) method (computed using the "lqmm" package in R). For this analysis, as we were interested in exploring individuals attending ED the most often, 90th, 97th, 99th and 99.7th quantiles were chosen in addition to the median for reference.

5.3.4 Bi-modal Lognormal Distribution

After observing the distribution of the time taken for an individual to attend an ED following contact with NHS 111, it became clear that although a large proportion of individuals attend soon after the call, a notable proportion attend a number of hours after the call. When visualising this data on a log scale (natural log) this displayed two symmetric bell-shape curves – one large curve for those attending shortly after the call, and one smaller curve for those taking a longer period of time to attend. Although the shape and position of these curves differed across the call dispositions provided, a similar bi-modal pattern was found for all non-ambulance dispositions. However, the time taken to attend an ED following an ambulance call-out differed from the other dispositions as it likely measured the response and treatment time of ambulance services, rather than parental/caregiver health-seeking behaviours. To compare the distributions of the time taken to attend ED across the dispositions, bi-modal lognormal mixture distributions were fit to this data for each disposition. Hence we assumed the time taken to attend an ED to be an independent lognormal mixture random variable with the following probability density function:

$$g(x;\mu_1,\sigma_1,\mu_2,\sigma_2,p) = (1-p)f(x;\mu_1,\sigma_1) + pf(x;\mu_2,\sigma_2), \quad p \in [0,1]$$

With $f(x;\mu_i,\sigma_i)$ denoting the probability density function of a lognormal random variable:

$$f(x;\mu_i,\sigma_i) = \frac{1}{\sqrt{2\pi}\sigma_i} e^{\frac{-(\log(x)-\mu_i)^2}{2{\sigma_i}^2}} \qquad i = 1,2 \qquad x > 0$$

Where μ_i and σ_i denote the mean and standard deviation of the log-transformed time taken to attend ED data (for the two waves of attendances) respectively. In the above lognormal mixture density function, the parameter p denotes the probability an individual's time taken to attend data belong to either of the two distributions. To provide maximum likelihood

estimates of the parameters for the lognormal mixture distribution, an expectation maximisation algorithm was computed for each call disposition using the "em" package in R.

5.3.5 Power Law Distribution

In the second study conducted in this PhD it was hypothesised that the number of yearly ED attendances made by C&YP is heavy tailed. Hence the analysis tested the fit of a number of statistical distributions including the discrete power law distribution. The probability mass function of a power law distribution is given by:

$$f(y) = ky^{-\alpha} \quad y \in \mathbb{Z}, k \in \mathbb{R}, \alpha \in \mathbb{R}$$

Where α is termed the power law scaling parameter and k is a constant. The parameter α a minimum point for which the power law fit begins is estimated by numerically optimising the log likelihood of the distribution.

5.3.5.1 Testing the Power Law Hypothesis

To test whether the number of yearly ED attendances made by C&YP follows a power law distribution, the following hypothesis was tested using a goodness of fit test:

H0 : data is generated from a power law distribution.

H1 : data is not generated from a power law distribution.

A Kolmogorov-Smirnov hypothesis test was carried out using a bootstrap procedure (powerlaw package in R), with a p-value sufficiently close to zero providing evidence to reject the null hypothesis (suggesting the data is unlikely to be generated from a powerlaw distribution).

5.3.5.2 Comparing Distributions

To compare the fit of a power law distribution to the yearly ED attendance data, a likelihood ratio test (Vuong's test) was implemented to compare if a discrete lognormal, discrete exponential or poisson distribution provided a better fit of the data. This test tests the null hypothesis that the two models are equally close to the true data generating process, against the alternative that one model is closer. Hence a sufficiently small p-value provides evidence to suggest a statistical distribution can be favoured over another.

5.3.6 Herfindahl Index

To quantify the heterogeneity of reasons for ED attendances by high frequency ED users, a Herfindahl index[120] was calculated for each individual. The Herfindahl index provides a value between 0 and 1 and relates to the number of different attendance reasons across individuals. For a sequence of consultations including N different categories; and where P_i represents the proportion of consultations belonging to the i^{th} category[121]:

$$Herfindahl\ index = \sum_{i=1}^{N} P_i^2$$

A value close to one indicates the patient made a large proportion of attendances for the same reason (low heterogeneity) and a value closer to zero indicates the patient made attendances for different reasons (high heterogeneity).

5.4 Overview of Methods

All the analyses conducted during this PhD used data from the CUREd research database. In particular, the data was used to produce four retrospective observational studies for C&YP.

5.4.1 Study 1: Use of Emergency Departments by Children & Young People Following Telephone Triage: A Large Database Study

This was a retrospective cohort study carried out on C&YP (≤17) attending an ED in the Yorkshire & Humber region of the UK following contact with NHS 111 between March 2016 and April 2017. This study linked NHS 111 call and ED attendance data and examines patient characteristics, NHS 111 pathways and ED outcomes. Bimodal lognormal mixture distributions were fit to compare the time taken to attend for different call dispositions. Logistic mixed effects regression models were used to identify predictors of low acuity NHS 111 related ED attendances and included variables such as age and deprivation status.

5.4.2 Study 2: Examining Statistical Distributions and Models for Analysis of Emergency Department Attendance Rates by Children & Young People

This was a retrospective cohort study was carried out on C&YP (≤17) attending an ED in the Yorkshire & Humber region of the UK between March 2016 and April 2017. Standard (poisson and negative binomial) and heavy tail (discrete lognormal, discrete exponential and powerlaw) distributions were fit to data relating to the number of ED attendances individuals made in the year. A number of statistical tests were computed to test the fit of these distributions to the data. To determine the best fitting generalised linear model for examining factors associated with high frequency ED use, a negative binomial, poisson, zero truncated poisson and zero truncated one inflated poisson model was fit using age as an explanatory variable. The fit of these models were compared using the AIC. Quantile regression models were then fit across a number of quantiles and proposed as a model for examining rates of attendance in those attending ED the most often.

5.4.3 Study 3: Exploring Factors Associated with High frequency Emergency Department Attendance in Children & Young People: A Retrospective Cohort Study

This was a retrospective cohort study carried out on C&YP (≤17) attending an ED in the Yorkshire & Humber region of the UK between March 2016 and April 2017. Factors associated with high frequency ED use were explored using a modified poisson regression model to assess the association between sex, age, ethnicity and deprivation status on rates of attendance. A quantile regression model was also fit to specifically explore the association of the above patient characteristics in those making the most attendances.

5.4.4 Study 4: Exploring High Frequency Emergency Department Use and Heterogeneity of Reasons for Attendance by Children & Young People: A Retrospective Cohort Study

In this study we analysed data for ED attendances made over two consecutive 12 month periods (beginning with the date of an individual's first attendance) by C&YP under the age of 15 in the Yorkshire and Humber region of the UK. Alluvial plots were produced to show the number of ED attendances individuals made in each of their two observation years (by age and deprivation). Reasons for attendance were extracted for individuals making 7-13 attendances over their two year observation period, and a Herfindahl index computed to determine the heterogeneity of reasons for attendance in individuals. We produced boxplots and fitted a linear regression model to determine the association between age and deprivation and heterogeneity of reasons for attendance.

5.5 Chapter Summary

This chapter outlines how and why EHRs (collected and stored in the CUREd research database) are analysed to address the research objectives in this PhD. The strengths and limitations of using routinely collected patient data are also outlined. Due to heterogeneity between primary research objectives, a variety of methods and statistical approaches were utilised (these were outlined in this section). The next section outlines the first data analysis study in this PhD and addresses the primary research objective which seeks to understand more about the relationship between NHS 111 pathways and ED outcomes for C&YP.

6 Use of Emergency Departments by Children & Young People Following Telephone Triage: A Large Database Study

Submitted for publication

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6.1 Chapter Outline

As NHS 111 is often an initial point of contact for parents and caregivers concerned about their child's health, examining UEC pathways of C&YP who are triaged by NHS 111 provided an important starting point for the analysis in this PhD. The systematic review conducted in relation to telephone triage in C&YP found that although advice provided during calls was generally followed by parents and caregivers, it may have led to a number of inappropriate ED attendances. This review demonstrated a clear gap in the evidence when considering the full picture of where C&YP were triaged to by NHS 111 and whether they subsequently used other UEC services such as EDs. Hence the motivation behind this study was to fill this evidence gap by determining the dispositions NHS 111 provided during calls for C&YP and whether other UEC services were then used. This study also aimed to understand parental and caregiver behaviours by analysing the time taken to attend an ED following contact with NHS 111 and subsequent ED outcomes. This provided insights into the perceived urgency of their child's healthcare need.

6.2 Abstract

Background Although one of the main objectives of NHS 111 is to ease the strain on urgent and emergency care (UEC) services, studies indicate that the telephone triage service may be contributing to increased demand for services such as emergency departments (EDs). For children and young people (C&YP), parents & caregivers generally find NHS 111 satisfactory, but concerns exist about call handler expertise, integration with the healthcare system, and appropriateness of the advice provided. Limited research focuses on NHS 111 pathways and subsequent ED outcomes in C&YP.

Objective To understand more about the relationship between NHS 111 pathways and ED outcomes for C&YP.

Methods A retrospective cohort study was carried out of C&YP (≤17) attending an ED in the Yorkshire & Humber region of the UK following contact with NHS 111 between March 2016 and April 2017. This study linked NHS 111 call and ED attendance data and examines patient characteristics, NHS 111 pathways and ED outcomes. Bimodal lognormal mixture distributions were fit to compare the time taken to attend for different call dispositions. Logistic mixed effects regression models were used to identify predictors of low acuity NHS 111 related ED attendances, and included variables such as age and deprivation status.

Results Our study of 348,401 calls to NHS 111 found that 45,746 (13.3%) led to an ED attendance within 24 hours. The time to attend ED could be categorised into two relatively distinct waves, with most attending soon after the call and a proportion attending later. Of those attending an ED after being told to do so by NHS 111, over a quarter resulted in a low acuity attendance.

Conclusions As younger children are often triaged by NHS 111 and treated in the ED, this highlights the need for more tailored healthcare services for this demographic. Both early low acuity attendance and late high acuity attendance following contact with NHS 111 could act as useful entry points for clinical audits of UEC use.

What is already known on this topic

- NHS 111 is likely contributing to increased demand for UEC services such as EDs in C&YP.
- Parents/caregivers have expressed concerns about call handler expertise, integration with the healthcare system, and appropriateness of the advice.

What this study adds

- Those who attend an ED after an NHS 111 call generally do so promptly, irrespective of the disposition provided.
- Of NHS 111 calls provided with an ED disposition, compliance was low with only 41% leading to an ED attendance within 24 hours, 28% of which being defined as low acuity.
- Younger children were more likely to make low acuity NHS 111 related ED attendances than older children.

How this study might affect research, practice or policy

- As younger children were more likely to make low acuity NHS 111 related ED attendances, this highlights the need for tailored healthcare services and resources for this age group, as they appear to be more frequently seeking care through NHS 111 and EDs.
- Both early low acuity attendance and late high acuity attendance could act as useful entry points for clinical audits of UEC pathways for C&YP.

6.3 Background

Telephone triage is a process for assessing the severity of a patient's injury or illness, assigning priorities and directing patients to the appropriate place for treatment before face to face contact.[122] In England, the medical telephone triage service NHS 111 forms an important component in the provision of urgent and emergency care (UEC), with callers receiving a largely algorithm based assessment ("NHS Pathways") to determine the most appropriate healthcare service for their clinical need.[123] NHS 111 was introduced to ensure more appropriate (and more timely) emergency department (ED) attendances, whilst reducing avoidable ones.[124] This was driven by patient feedback suggesting it is often difficult to know which NHS service to contact for routine or urgent care, specifically when access to a general practitioner (GP) is limited.[125] Reduction in pressure on UEC services is also a major driver of NHS 111, demonstrated by recent NHS winter campaigns designed to encourage individuals to contact NHS 111 prior to attending UEC services.[126] [127] However, the effectiveness of NHS 111 in reducing the demand for UEC services has been questioned by medical professionals and researchers alike, with studies conducted in the early years of NHS 111 suggesting that the telephone triage service may actually be contributing to an increase in the demand for these services.[51]

Many children and young people (C&YP) seen in ED or primary care are triaged through NHS 111.[128] Although C&YP present a challenge to NHS 111 due to the clinical judgement usually required when diagnosing these patients, parents and caregivers were generally satisfied with the care provided for C&YP during calls. However, there were concerns raised about the clinical expertise of call handlers, the need for better integration with other parts of the healthcare system and the appropriateness of the advice provided in the call.[129] A systematic search for publications in the design of this research found only three quantitative

studies exploring data collected within the UK when considering C&YP [72, 74] (with only one study analysing data collected from NHS 111 calls [73]). As NHS 111 is a nationwide unified system which differs greatly from other smaller scale (either state or ED specific) telephone triage services, exploring NHS 111 pathways is beneficial to the field of health-related research especially when considering C&YP, who are more likely to make avoidable ED attendances after contacting NHS 111 than adults.[24]

We aimed to understand more about the relationship between NHS 111 pathways and subsequent ED outcomes for C&YP. In particular we focused on two aspects of triage: first when parents and caregivers of C&YP with minor problems overrule triage advice (e.g., by attending ED promptly despite advice to follow other pathways) and second when triage to non-ED care is followed by hospital admission.

6.4 Methods

6.4.1 Study Design

Retrospective cohort study.

6.4.2 Patient And Public Involvement

Patients were not directly involved in the planning or execution of this research which analysed routinely collected healthcare data.

6.4.3 Competing Interest

No competing interest.

6.4.4 Research Ethics Approval: Human Participation

No human participation in this study.

6.4.5 Data Used

This study used data collected from the "Connected Health Cities: Data linkage of urgent care data" study (known as the "CUREd research database").[130] The CUREd Database has approval from the National Health Service (NHS) Research and Ethics Committee, overseen by the NHS Health Research Authority's Research Ethics Service, and from the NHS Health Research Authority (HRA), directly, to receive health and social care data without patient consent for patients of emergency and urgent care services in Yorkshire and Humber. The CUREd research database holds data from NHS 111 calls, emergency ambulance incidents,

ED attendances and emergency admissions to hospitals in the Yorkshire and Humber region of the UK. Each entry has an anonymised common patient identifier code to facilitate linkages across the datasets.[131] This study used data from the NHS 111 calls and ED datasets (348,401 calls and 420,051 attendances respectively) for C&YP aged 17 and under, in the period March 2016-April 2017. The NHS 111 calls dataset consisted of calls made to the NHS 111 telephone service operated by The Yorkshire Ambulance Service NHS Trust. The ED dataset consisted of patient records (items mandated by the national Commissioning Dataset-CDS) for attendances made to the 13 participating Hospital Trusts' Emergency Departments (EDs). An ED attendance was defined as an unplanned ED attendance made to a type 1 ED, type 2 ED or other type of ED with designated accommodation for the reception of ED patients.

6.4.6 Data Management

6.4.6.1 Data Extraction

The data extraction, cleaning, linking and statistical analyses were performed using R-Studio (version 4.1.1) including the "mclust", "mixtools" and "lme4" packages.[132] From the NHS 111 Call dataset the following items were extracted: anonymised patient identifier code, unique record identifier, sex of patient, age at call, incident index of multiple deprivation, date/time of call, episode end date/time, episode length and final disposition description. From the ED attendance dataset the following items were extracted: Anonymised patient identifier, encrypted attendance record identifier, sex of patient, ethnicity of the patient, incident index of multiple deprivation (IMD), age on arrival, arrival mode, referral information, attendance disposal, arrival date/time, conclusion time and low acuity attendance indicator. The distribution of patients by IMD quintiles in the data was not even; this reflects both the demography of Yorkshire and Humber generally – with more people

living in deprived areas than the English average, and greater ED use by people of lower sociodemographic status.

6.4.6.2 Data Linkage

To identify ED attendances that occurred following the use of NHS 111, the ED and NHS 111 datasets were first linked using patient ID, and then date and time. We set the threshold for linkage as ED attendance arrival date/times occurring within 24 hours of an NHS 111 call. A 24 hour threshold was used to accommodate for the fact that patients may have been provided with a 24 hour NHS 111 call disposition (such as "attend primary care service within 24 hours"). In the case that multiple NHS 111 calls were made within 24 hours of an ED attendance, the final NHS 111 call was used in the linked dataset. In the case that multiple ED attendances occurred within 24 hours of a single NHS 111 call, the first attendance was used in the linked dataset to avoid multiple representations.

6.4.7 Definitions

6.4.7.1 NHS 111 Call Dispositions

For calls made to NHS 111:

- A recommended to attend ED- "ED" disposition occurred when the caller was advised to attend an ED within a given time frame, by their own means.
- An emergency ambulance sent- "Ambulance Dispatched" disposition occurred when the NHS 111 call handler transferred the call to 999 for an ambulance response.
- A recommended primary, community or other care- "Primary care" disposition occurred when the call handler recommended the use of primary care services such as

a GP, dental practitioner, community pharmacy, mental health services or a district nurse.

- A not recommended to attend other service-"Home care" disposition was provided when the patient was advised: home care or the use of none of the aforementioned services.
- In the event that a caller terminated the call, these calls were grouped into a "Caller Terminated Call" category.

6.4.7.2 Time Taken to Attend ED Following an NHS 111 Call

The time taken to attend an ED following contact with NHS 111 was calculated by finding the difference between the conclusion time of an NHS 111 call, and the subsequent arrival time at an ED. For patients who received a call-back from NHS 111, the call conclusion was defined as the time a call episode was ended by the call handler.

6.4.7.3 NHS 111 Related ED Attendance

An NHS 111 related ED attendance was defined as an unplanned ED attendance made by a patient within 24 hours of the NHS 111 call conclusion.

6.4.7.4 Attendance Acuity

A low acuity ED attendance field was defined as an attendance made to a type 1 ED meeting the following 3 conditions [133]:

- Attendance produced at least one of the following investigation codes: None, urinalysis, pregnancy test or dental investigation.

- Attendance produced at least one of the following treatment codes: Prescription(s), guidance/advice only, recording vital signs, dental treatment or no investigation.
- Attendance produced at least one of the following disposals: Discharged (following treatment to be provided by GP/no follow up treatment required) or left department before being treated.

A high acuity ED attendance was defined as an attendance that resulted in the patient being admitted into hospital, and an intermediate acuity ED attendance was defined as all attendances not falling into the low or high acuity attendance category.

6.4.7.5 NHS 111 Related ED Attendance Pathways

For ED attendances occurring after non-ED call dispositions (home care, primary care and caller terminated call), referral information was obtained and categorised into three groups, patients who self-referred to the ED, patients referred by a GP or other healthcare provider and patients referred by local authority social services, educational/work establishment, police and other non-medical services. The final category also contained missing referral values.

6.4.8 Statistical Analysis

6.4.8.1 Patient and Call Characteristics

Descriptive statistics were used to provide a summary of key call and ED attendance characteristics. The patient characteristics summarised were sex, age, ethnicity and IMD status.

6.4.8.2 Time Taken to Attend an ED Following an NHS 111 Call

Initial inspection of the data indicated a bimodal distribution of the skewed time to attend following an NHS 111 call for all dispositions. These bimodal distributions were decomposed into two overlapping distributions representing a first and second wave of attendance using a bimodal lognormal mixture method. This is described in more detail in section 5.3.4. Individuals were allocated to the early wave if their time to attend was between 0 and the upper quartile of the first wave, and the second wave if their time to attend was between the lower quartile of the second wave and 24 hours (all remaining individuals were allocated to an intermediary category).

6.4.8.3 Predictors of Low Acuity NHS 111 Related ED Attendances

Logistic mixed effects regression models were computed to find predictors of low acuity NHS 111 related ED attendances in C&YP for each of the call dispositions. The fixed effects variables considered in these models were: the age, sex, IMD status of the patient and whether the call was made out-of-hours. Patient level random effects were also accounted for in these models.

6.5 Results

6.5.1 Patient, Call and Attendance Characteristics

In the period April 2016-March 2017, 348,401 calls were made to NHS 111 concerning 227,219 C&YP aged 17 and under in the Y&H region of the UK. Of these calls 79,331 (22.7%) involved the assistance of a clinical advisor when providing advice. There was a relatively even split of male and female call subjects (51.6% being male), although the age demographic was skewed towards younger children with the majority of the call subjects being aged 0-4 (60%) (see Table 15).

Table 15-NHS 111 Patient Information

Characteristics	NHS 111 Users N=227,219		NHS 111 Related ED Users N=40,715	
	n	%	n	%
Sex				
Male	117,224	51.6	21,323	52.4
Female	108,119	47.6	19,392	47.6
Missing	1,876	0.8	-	-
Age Group				
<1	57,423	25.3	8,547	21
1-4	78,617	34.6	16,639	40.9
5-9	45,243	19.9	7,062	17.3
10-14	26,108	11.5	4,537	11
15-17	19,828	8.7	3,927	9.6
Missing	3	0.01	3	0.01
Ethnicity				
White	-	-	29,927	73.5
Asian	-	-	5,187	12.7
Black	-	-	642	1.6
Mixed Ethnicity	-	-	1,493	3.7
Other Ethnicities	-	-	852	2.1
Missing	-	-	2614	6.4
IMD Status				
1 (Most Deprived)	85,066	37.4	18,030	44.3
2	37,820	16.6	7,421	18.2
3	31,066	13.7	5,675	13.9
4	31,059	13.7	5,543	13.6
5 (Least Deprived)	23,441	10.3	3,963	9.7
Missing	18,767	8.3	83	0.2

Of the calls made to NHS 111, 46,970 (13.4%) resulted in an ED attendance within 24 hours of the call conclusion. Figure 6 shows the dispositions provided during calls and the proportion resulting in an ED attendance. After excluding 1,224 attendances for which the ED attendance date/time was missing, this left 45,746 (13.3%) calls for inclusion in the analysis. These attendances were made by 40,715 distinct individuals. For the 45,746 NHS 111 related ED attendances, the dispositions provided in calls were: Ambulance Dispatched (9,171, 20%), ED (14,144, 30.9%), primary care (14,870, 32.5%), home care (601, 1.3%) and caller terminated call (6,775, 14.8%).

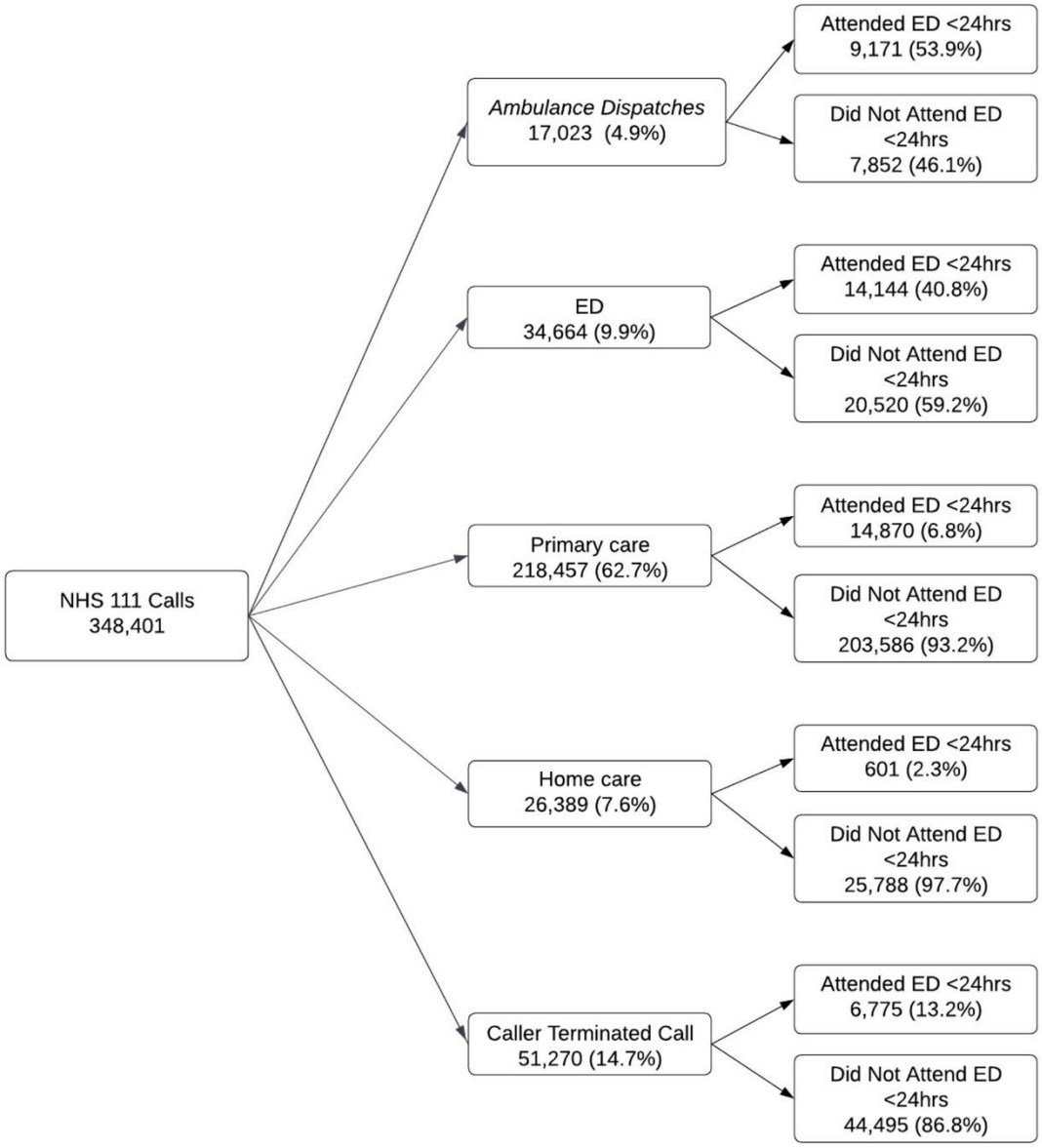

Figure 6-Call Disposition and Subsequent ED Use

6.5.2 Distribution of the Time Taken to Attend an ED Following an NHS 111 Call

The time between the call conclusion and ED arrival approximately followed a bimodal lognormal mixture distribution with two distinct waves of attendances, split by those who attended quickly after the call (early attenders), and those who attend less quickly after the call (late attenders, see Figure 7).

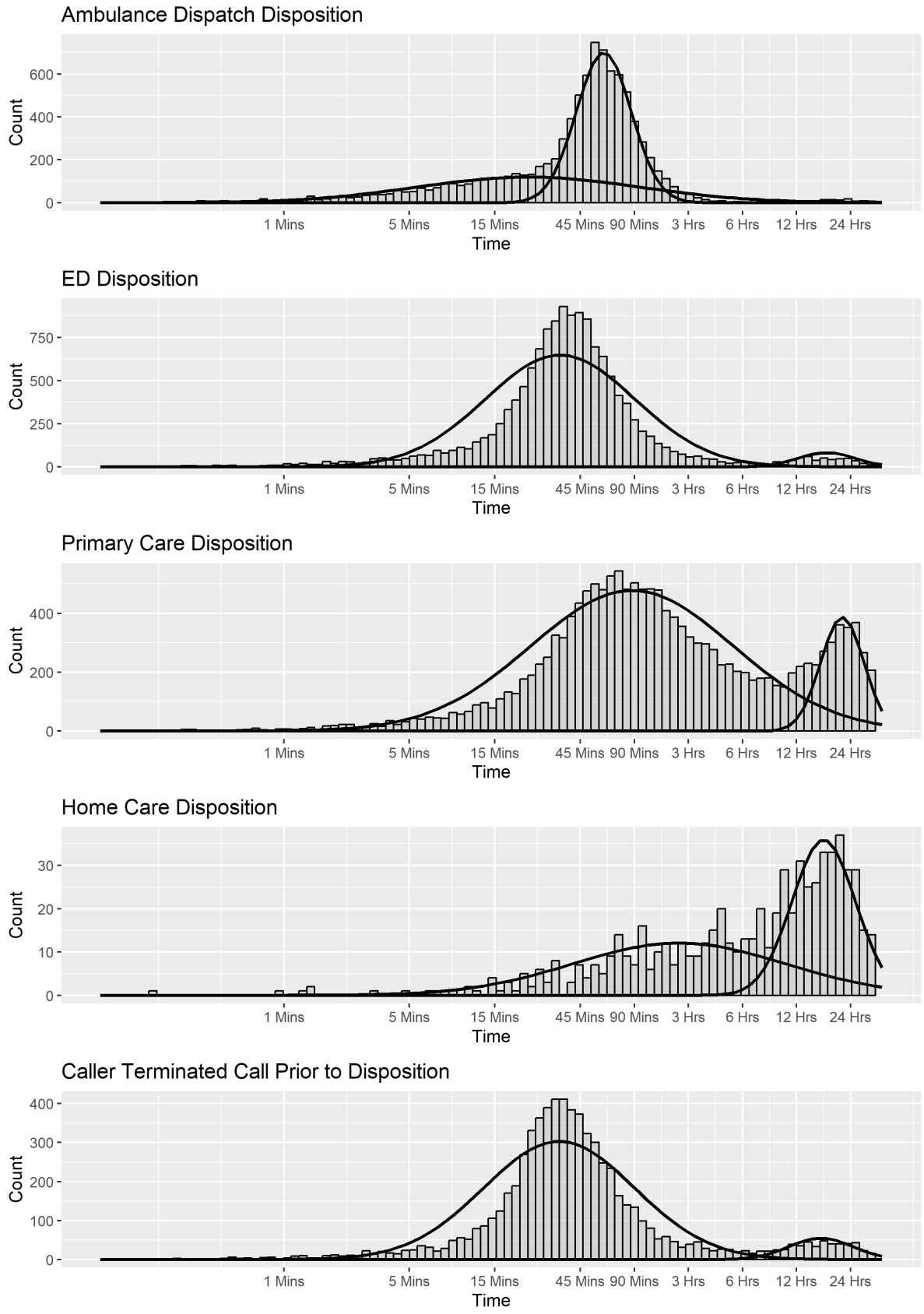

Figure 7-Fitted Distribution of Time taken to Attend ED Following NHS 111 Disposition (log-scale)

Overall, although 75% of all NHS 111 related ED attendances occurred relatively soon after the call conclusion (within just 103 minutes all dispositions), the magnitude and shape of the two waves of attendances depended on the disposition provided during the call (see Table 16).

Table 16-Expectation-Maximisation Estimates of Bi-modal Lognormal Mixture Parameters

Disposition	Proportion of individuals in first wave (%)	Lower Quartile of first wave (hrs)	Median of First wave (hrs)	Upper Quartile of first wave (hrs)	Proportion of individuals in second wave (%)	Lower Quartile of second wave (hrs)	Median of second wave (hrs)	Upper Quartile of second wave (hrs)
Caller Terminated Call	93	0.3	0.6	1.2	7	10.7	16.4	25
Home care	53	1.2	2.7	6.1	47	10.7	17	25
Primary care	85	0.7	1.5	3.2	15	16.4	21.5	30
ED	95	0.3	0.6	1.2	5	11.9	17.6	27.8
Ambulance Dispatch	41	0.4	0.7	1.2	59	0.7	1	1.4

The majority of ED attendances following an ED call disposition occurred within a short timeframe (95.3% in the first wave, median time 35 minutes), indicating prompt response to advice. Attendances after caller-terminated calls mirrored those with ED dispositions. Among late ED attendances following NHS 111 triage to primary care, there was a higher rate of high acuity attendances (see Table 17).

6.5.3 Predictors of low Acuity NHS 111 Related ED Attendances

Of the 23,315 ED attendances either advised to attend ED or had an ambulance dispatched by NHS 111, 5,745 (24.6%) were defined as low acuity and 4,106 (17.6%) were defined as high

acuity. Of the 22,720 ED attendances not advised to attend ED (home care, primary care and caller terminated call), 5,147 (22.7%) were low acuity whereas 5,319 (23.4%) of attendances were defined as high acuity attendances. For all call dispositions, age was a statistically significant predictor of low acuity NHS 111 call related ED attendances, with younger patients (<1) being more likely to make these attendances in comparison to older individuals. Whether the call was made out of working hours (weekdays 8am-6pm) was not a statistically significant predictor of low acuity ED attendances (see Table 18).

Table 17-ED Attendance Pathways and Outcomes Following Contact with NHS 111

NHS 111 Disposition	ED Referral	Low Acuity ED Attendance			Intermediate Acuity ED Attendance			High Acuity ED Attendance		
		N	Time[4]	%	N	Time	%	N	Time	%
Ambulance	-	1,726	52	18.8	4,759	51	51.9	2,686	52	29.3
ED	-	4,019	38	28.4	8,705	38	61.6	1,420	37	10
Primary care	Self	2,235	85	24.2	5,199	100	56.1	1,820	117	19.7
	GP/Healthcare Provider	681	96	17.9	1,563	122	40.9	1,571	122	41.2
	Other/Missing	515	66	28.6	857	79	47.6	429	102	23.8
Home care	Self	112	494	27.3	259	467	63.2	39	271	9.5
	GP/Healthcare Provider	27	430	29	39	374	42	27	654	29
	Other/Missing	32	431	32.7	59	473	60.2	7	149	7.1
Caller Terminated Call	Self	845	39	21.6	2,468	38	63.1	597	39	15.3
	GP/Healthcare Provider	289	36	19.2	859	34	40.3	361	37	23.9
	Other/Missing	363	36	26.7	689	36	50.8	306	34	22.5

[4] Time is the median time taken (mins) to attend ED following the conclusion of an NHS 111 call.

Table 18-Predictors of Low Acuity ED Attendances Following Contact with NHS 111 (Logistic Mixed Effects)

	Home care		Primary care		ED		Ambulance		Caller Terminated Call	
	OR	CI	OR	CI	OR	CI	OR	CI	OR	CI
Predictor										
Sex										
Male (ref)	-	-	-	-	-	-	-	-	-	-
Female	1.05	0.72-1.53	1.05	0.97-1.14	0.93	0.86-1.00	0.96	0.86-1.07	0.92	0.82-1.04
Age										
15-17 (ref)	-	-	-	-	-	-	-	-	-	-
<1	1.35	0.57-3.19	1.60	1.36-1.88	2.06	1.74-2.44	2.06	1.65-2.56	1.76	1.39-2.23
1-4	1.47	0.67-3.22	1.39	1.19-1.62	1.91	1.64-2.23	1.96	1.59-2.42	1.60	1.29-1.98
5-9	1.07	0.45-2.51	1.35	1.14-1.61	1.32	1.12-1.57	1.90	1.48-2.45	1.41	1.11-1.79
10-14	1.86	0.32-2.28	1.06	0.87-1.30	1.05	0.87-1.26	1.59	1.20-2.10	1.11	0.86-1.43
Deprivation										
5-Least Deprived (ref)	-	-	-	-	-	-	-	-	-	-
1-Most Deprived	1.50	0.74-3.02	1.00	0.87-1.16	0.87	0.77-0.99	0.95	0.78-1.17	0.88	0.72-1.08
2	1.14	0.53-2.45	0.97	0.83-1.14	0.79	0.69-0.91	0.82	0.66-1.03	0.86	0.69-1.09
3	0.73	0.32-1.70	0.98	0.82-1.16	0.85	0.73-0.99	0.99	0.79-1.25	1.09	0.86-1.37
4	0.88	0.38-2.02	0.97	0.81-1.15	0.98	0.85-1.14	1.20	0.96-1.52	1.06	0.84-1.34
Call Made Out-of-Hours										
No (ref)	-	-	-	-	-	-			-	-
Yes	1.04	0.71-1.53	0.95	0.87-1.02	0.96	0.88-1.03	0.97	0.87-1.09	0.96	0.85-1.08
N	552		13,582		12,740		8,526		6154	

6.6 Discussion

6.6.1 Summary of Principal Findings

Our study of 348,401 calls to NHS 111 for C&YP found that 13.3% led to an ED visit within 24 hours, primarily among children aged 0-4. Time to attend ED could be categorised into two relatively distinct waves, with most attending soon after the call and a proportion of outliers who attend later. Younger age was a predictor of low acuity ED attendance across all NHS 111 dispositions. The majority of ED attendances following an ED call disposition occurred within a short timeframe (95.3% in the first wave, median time 35 minutes), indicating prompt response to advice. Attendances after caller-terminated calls mirrored those with ED dispositions.

6.6.2 Strengths and Limitations

To our knowledge, this is the largest linked data study of NHS 111 related ED attendances regarding C&YP. The existence of a low acuity measure in the CUREd dataset allowed us to specifically explore novel predictors of non-urgent NHS 111 related ED attendances in C&YP. A limitation of this study was that we could not ascertain specific details of primary care attendances due to a lack of linkable primary care data, hence compliance and the appropriateness of primary care dispositions could not be deduced in this analysis.

6.6.3 Comparison with other Studies

Other studies have explored characteristics of ED use following contact with NHS 111 in C&YP.[73] Younger children were similarly found to being the most likely to have a call made

on their behalf. To our knowledge no previous studies have examined time to attend ED following an NHS 111 call.

6.6.4 Implications for Practice and Further Research

For those not told to attend ED by NHS 111, compliance with the advice (in relation to ED use) was high with only 7.5% of individuals attending an ED within 24 hours of the call. However, those that did attend generally attended promptly, with a broadly similar distribution of times to arrival as individuals advised to proceed to the ED. This suggests that NHS 111 advice was being disregarded by caregivers, rather than other steps being taken first. The proportion of these attendances which were deemed high acuity was small suggesting that parental concern may be a dominant factor. As the distribution of time taken to attend was analogous for those terminating the call and those provided with an ED disposition, this could suggest that some parents and caregivers were unhappy with the telephone triage process, thus terminating the call early and attending ED promptly. This finding provides an opportunity for future qualitative research to explore insights as to why these parents and caregivers terminated the call prior to a disposition being reached. Among late ED attendances following NHS 111 triage to primary care, there was a higher rate of high acuity attendances. It is not possible from this data to tell whether this was a consequence of progression of illness crossing appropriate safety-netting thresholds or unnecessary treatment delay. Both early low acuity attendance and late high acuity attendance could act as useful entry points for clinical audits of UEC pathways for C&YP.

6.6.5 Conclusion

As younger children are often triaged by NHS 111 and treated in the ED, this highlights the need for more tailored healthcare services for this demographic. Both early low acuity attendance and late high acuity attendance following contact with NHS 111 could act as useful entry points for clinical audits of UEC use.

6.7 Chapter Summary

This chapter explored UEC pathways for C&YP after contact with the telephone triage service NHS 111. Compliance in relation to ED use was high when an individual was provided with a non-ED disposition, but low when provided with an ED disposition. Younger age was found to be associated with low acuity ED attendances following contact with NHS 111 irrespective of the disposition. In particular, infants under the age of one were found to be two times more likely to make a low acuity ED attendance than the oldest children (15-17) when provided with an ED disposition by NHS 111. Hence this chapter concluded that NHS 111 may be directing C&YP to an ED when other services may have been more appropriate. This chapter has provided useful insights into the use of NHS 111 by parents and caregivers when determining the most appropriate healthcare service to treat their child. The next chapter explores explore C&YP who make a number of ED attendances in a given period, with specific emphasis placed on examining methods of assessing factors associated with this.

7 Examining Statistical Distributions and Models for Analysis of Emergency Department Attendance Rates by Children & Young People

In preparation for publication to Emergency Medicine Journal

Kumar, A., Kerryn, H., Simpson, R., Johnson, G., Burton, C. 2023. Examining Statistical Distributions and Models for Analysis of Emergency Department Attendance Rates in Children & Young People.

7.1 Chapter Outline

The previous section outlined the UEC pathways C&YP take following contact with NHS 111. Although the study found that parents and caregivers often followed the advice provided during NHS 111 calls, as a notable proportion disregarded the advice (or terminated the call), this demonstrates the importance of parental/caregiver decision making when determining the most appropriate healthcare service for their child. This decision making process comprises a number of factors including the perceived urgency of their child's healthcare needs but may also be due to socioeconomic considerations. When considering high frequency ED use, the systematic review conducted in this PhD found that an individual's medical insurance status was associated with high frequency ED use. As uninsured or underinsured individuals were more likely to reside in areas with greater levels of deprivation, this suggested that socioeconomic factors such as lack of access to primary care services were associated with high frequency ED use. To explore these factors, studies often used a dichotomous approach to distinguish between high frequency and occasional ED users. Although this approach is useful to determine a ground truth when exploring factors associated with those who attend EDs frequently, it generally means study comparisons were often difficult (as there is no

universal definition for high frequency attenders). In addition to this, categorising high frequency attenders into two categories loses key information for those attending most often, as they are assumed to have similar characteristics with other less frequent attenders. Hence, the motivation behind this study was to first determine the statistical distribution underpinning the number of ED attendances C&YP make, and then to fit and test a number of regression models with the overarching aim of recommending an improved method of assessing factors associated with high frequency ED use.

7.2 Abstract

Background Although the majority of children and young people (C&YP) attend Emergency Departments (EDs) infrequently, a small proportion attend with higher frequency. Studies exploring high frequency attenders of EDs commonly define a high frequency attender as an individual making 4 or more attendances in a year period (however this differs across studies). When considering the factors associated with high frequency ED attendance, this definition is useful as it allows logistic regression models to be fit to determine odds ratios for a variety of patient-level explanatory variables such as age and sex. However, a limitation of defining a high frequency attender in this way is the fact that all individuals in a given category are assumed to have similar characteristics. Hence, to explore factors associated with rates of ED attendance in detail, removing the necessity to categorise high frequency attenders can be useful when comparing studies.

Objective To examine the underlying statistical distribution for the number of yearly ED attendances in C&YP and determine the most appropriate statistical regression models when analysing factors associated with rates of ED attendance in C&YP.

Methods A retrospective cohort study was carried out of C&YP (≤17) attending an ED in the Yorkshire & Humber region of the UK between March 2016 and April 2017. Standard (poisson and negative binomial) and heavy tail (discrete lognormal, discrete exponential and power law) distributions were fit to data relating to the number of ED attendances individuals made in the year period. A number of statistical tests were computed to test the fit of these distributions to the data. To determine the best fitting generalised linear model for examining factors associated with high frequency ED use a negative binomial, poisson, zero truncated poisson and zero truncated one inflated model was fit using age as an explanatory variable. The fit of these models were compared using the AIC. A quantile regression model was then

fit across a number of quantiles, and proposed as a model for examining rates of attendance in those attending ED the most often.

Results This study has provided evidence to suggest that the number of yearly ED attendances made by C&YP likely follow a heavy tail distribution such as the discrete power law or lognormal distribution. This study proposes the use of a zero truncated or one inflated zero truncated poisson model in combination with a quantile count regression to analyse ED attendance rates in C&YP.

Conclusions This study has shown that an adapted poisson regression model (zero truncated and one inflated zero truncated) can be used in combination with a quantile regression model to explore rates of ED attendance and provide insights into those attending ED the most often.

7.3 Background

Although the majority of children and young people (C&YP) attend Emergency Departments (EDs) infrequently, a small proportion attend with higher frequency.[85] Studies exploring high frequency attenders of EDs commonly define a high frequency attender as an individual making 4 or more ED attendances in a year period, but this threshold was found to differ across studies. [85, 86, 88, 89, 92, 94-97] This binary high frequency attender definition is often useful for studies exploring factors associated with high frequency ED attendance, as it ensures a relatively straightforward statistical analysis can take place using logistic regression. When considering factors associated with high frequency ED attendance, these models are fit to ED data to determine odds ratios for a variety of patient-level explanatory variables such as age and sex.[21, 84, 88-91, 93-97, 100-102] However, a limitation of defining a high frequency attender in this way is the fact that all individuals in a given category are assumed to have similar characteristics. For example, individuals attending extremely frequently with 15+ yearly ED attendances are assumed to have similar characteristics to those who make 4 attendances in a year, which may not necessarily be true. Instead of a dichotomous approach when defining a high frequency attender, it may be more desirable to use a continuous approach by modelling the total attendances an individual makes. For example, rather than assessing the odds of an individual being a high frequency attender, a small number of studies use count generalised linear models (count-GLMs) to assess the yearly rate of ED attendance in individuals.[85, 86] These models remove the binary categorisation requirement by analysing the number of yearly ED attendances an individual makes directly.

Examining the underlying distribution of yearly ED use in C&YP is crucial when determining the most appropriate statistical model for exploring the reasons for attendances in high frequency attenders. When considering high frequency attendance in adults, previous

studies have outlined the heavy-tail nature of an individual's ED attendance distribution, but this has not been examined in C&YP.[55] Assessing this in C&YP is important as these individuals have differing medical needs than adults (in addition to the existence of parent/caregiver involvement) meaning this distribution may differ for this demographic.

The objectives of this study are to:

- Determine the underlying distribution of yearly ED attendances made by C&YP.
- Compare the fit of a number of count-GLMs (using yearly ED attendance data) to determine the best model for assessing predictors of high frequency ED attendance in C&YP.
- Examine the advantages and disadvantages of each approach and make recommendations for use in analysis.

7.4 Methods

7.4.1 Patient And Public Involvement

Patients were not directly involved in the planning or execution of this research which involved routinely collected healthcare data.

7.4.2 Data Used

This study used data collected from the "Connected Health Cities: Data linkage of urgent care data" study (known as the "CUREd research database").[130] The CUREd research database holds record-level data from NHS 111 calls, emergency ambulance incidents, ED attendances and emergency admissions to hospitals in the Yorkshire and Humber region of the UK, and contains an anonymised common patient identifier code to facilitate linkages across the datasets.[131] The ED dataset consisted of patient records (items mandated by the national Commissioning Dataset-CDS) for attendances made to the 13 participating Hospital Trusts' Emergency Departments (EDs). An ED attendance was defined as an unplanned ED attendance made to a type 1 ED, type 2 ED or other type of ED with designated accommodation for the reception of ED patients. Attendances made to services that were mainly/entirely appointment based were excluded from this analysis.

7.4.3 Data Management

7.4.3.1 Data Extraction

This study extracted data from April 2016-March 2017. The following items were extracted from the ED attendance dataset: Encrypted patient identifier, encrypted attendance record

identifier and age on arrival. The data extraction, preparation and statistical analyses were carried out using R 4.2.1 (R Software Foundation).

7.4.3.2 Data Preparation

Age was categorised into the following age groups to coincide with other previously produced research: <1, 1-4, 5-9, 10-14 and 15-17. An ED attendance count variable was derived by aggregating the number of ED attendances an individual made in the year study period.

7.4.4 Overview of Statistical Models and Distributions

7.4.4.1 Generalised Linear Model

A generalised linear model (GLM) is a regression model that fits a dependent outcome variable, which is assumed to belong to a probability distribution in the exponential family class of distributions (including the normal, poisson, binomial and negative binomial distributions).[118] For this analysis, count-GLMs, defined as GLMs applied to non-negative integer outcome variables were considered (namely a negative binomial, poisson, zero-truncated poisson and zero truncated one inflated poisson regression model).[134] A logistic regression model was also fit to determine the odds of an individual being a frequent attender using the binary definition of frequent attendance (3+ attendances in the year). In addition to the initial assumption that a dependent variable must belong to an exponential family probability distribution, a linear predictor of explanatory variables must be linked by a link function to model the expected value of a dependent variable (ED attendance count in our case).[118]

7.4.5 Statistical Analysis

7.4.5.1 Exploring the Fit of Yearly ED Count Data Using Discrete Pearson Distributions

A discrete data Cullen and Frey (Skewness-Kurtosis) graph was initially plotted to visually assess the likelihood that the data follows a suitable discrete Pearson distribution[135] (negative binomial and poisson distribution) using the "fitdistrplus" package in R-Studio. A Goodness-of-fit test was then computed to determine the best fitting Pearson model (Chi-square test). The Goodness-of-fit criteria (Akaike Information Criterion-AIC [136]) was also computed to compare the fit of the models.

7.4.5.2 Examining the Underlying Distribution of Yearly ED Count Using Heavy-tail Distributions

Next, to investigate whether the yearly ED count showed characteristics of heavy-tail distributions, a three-step approach (derived from the Power-law paper by Clauset et al [137]) was implemented using the "poweRlaw" package in R-Studio.

- The parameters of a poisson, discrete lognormal, discrete exponential and discrete power law distribution were found (using maximum likelihood estimation) and graphically fit to the data to determine which distribution provided the best approximate fit. To provide a visual representation of the underlying distribution of the data, a plot of the complementary cumulative distribution function (CCDF) was produced on a log-scale. The CCDF is defined as the proportion of patients whose total number of contacts was greater than or equal to each number of contacts.
- Next the Goodness-of-Fit was computed by carrying out a Kolmogorov-Smirnov hypothesis test using the null hypothesis that the data belong to a discrete power law distribution. A bootstrap method was implemented to provide evidence to either

accept or reject this null hypothesis (in the case where the null hypothesis is rejected this implies that another distribution may be more appropriate).

- Finally, a likelihood ratio test (Vuong's test) was implemented to compare if a discrete lognormal, discrete exponential or poisson distribution provided a better fit to the data in comparison to the discrete power law distribution. This test provides a p-value, which when sufficiently small provides evidence to suggest that one model can be favoured over another.

7.4.5.3 Comparing the Fit of Count GLMs When Determining Factors Associated with High Frequency ED use

When determining the factors associated with a response variable that follows a heavy tail distribution such as the discrete power law distribution, it is still beneficial to find the best fitting count GLM as, to our knowledge there are few easily interpretable methods of conducting multivariable heavy-tailed regression. Hence, four GLMs (poisson, negative-binomial, zero truncated poisson and zero truncated one inflated poisson) were fit using a patient's yearly ED attendance count as a dependent variable, and the age of the individual as the explanatory variable. To compare the fit of the four count GLMs, the AIC [136] was calculated and compared. The model with the lowest AIC was assumed to provide a better fit of the data.

7.4.5.4 Fitting A Count Quantile Regression Model

When exploring predictors of a response variable, quantile regression can be used to focus on the upper tail of a distribution. The upper tail of the ED attendance distribution in this analysis described individuals attending ED the most often. Hence to capture the upper tail of

the ED attendance data, quantile regression models for count data were fit.[138] Unlike GLMs that estimates the expected value of the response variable, a quantile regression model estimates a given quantile of the response variable.[139] For this analysis, as we were interested in exploring individuals attending ED the most often, the 90^{th}, 97^{th}, 99^{th} and 99.7^{th} quantiles were chosen in addition to the median for reference. These quantiles were chosen to display how the association between high frequency attendance and age change when considering higher quantiles. The 99.7^{th} quantile was chosen in this case as the highest quantile as this was highest quantile for which the sample size of individuals was large enough for the model to converge. The age of an individual was used as an explanatory variable in the model.

7.5 Results

7.5.1 Underlying Distribution

In the period April 2016-March 2017, 420,051 ED attendances were made by 288,543 distinct C&YP aged 17 and under. The majority of these individuals (206,973, 71.7%) made one attendance in the year period but 4,999 (2%) patients made over 5 attendances, indicating the data may show some characteristics of a heavy tail distribution.

7.5.2 Exploring the Fit of Yearly ED Count Data Using Discrete Pearson Distributions

The Cullen and Frey graph (Figure 8) describes the skewness (a measure of symmetry), and kurtosis (a measure of whether the data is heavy tailed relative to a normal distribution) of the data.[140]

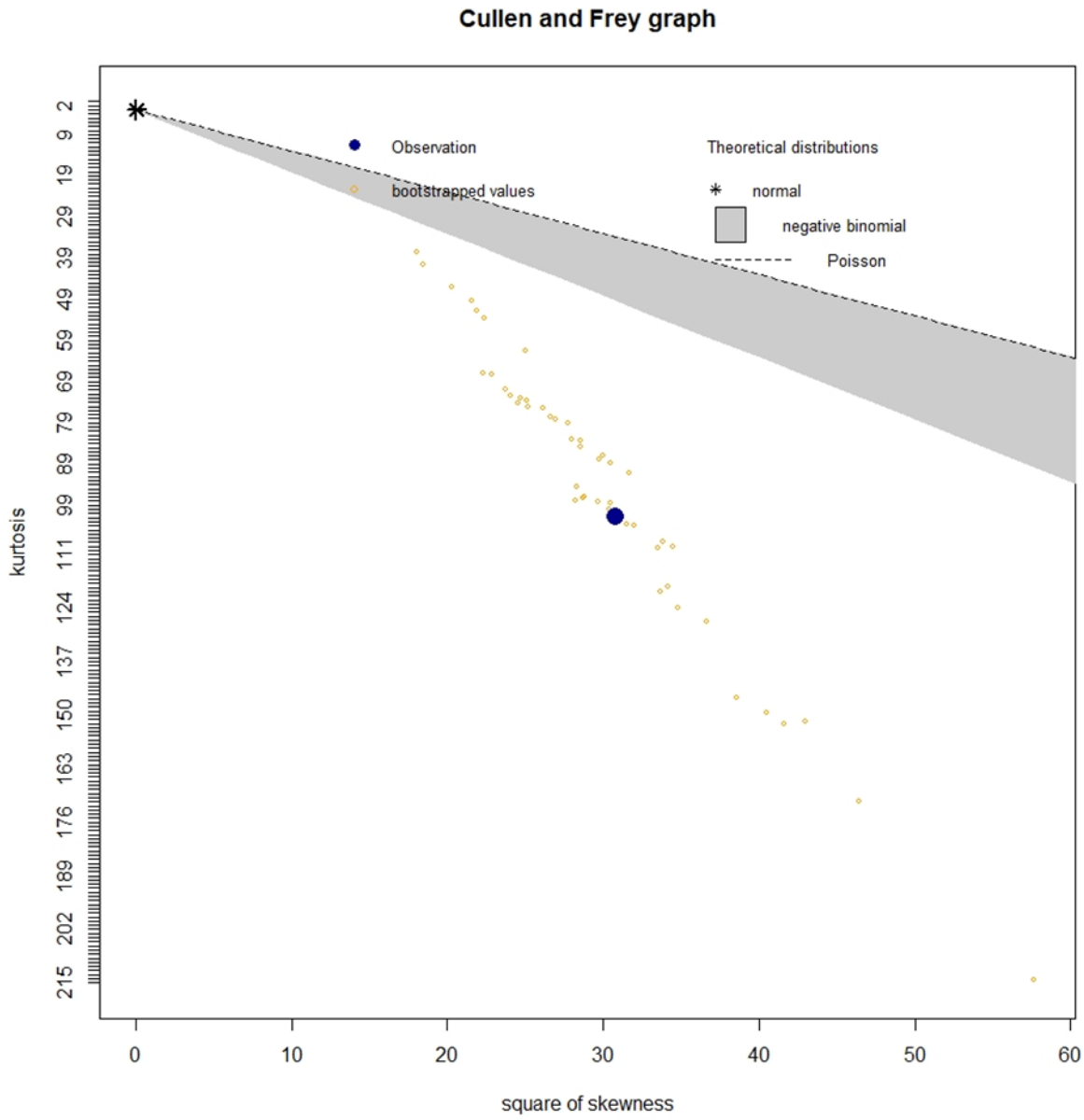

Figure 8-Cullen & Frey Graph to Show Fit of Yearly ED Count Data to Common Distributions

This demonstrated that the yearly ED count data was unlikely to follow either a poisson or negative binomial distribution. The blue circle (representing the data) indicated that the data produced a kurtosis of 99 and a square of skewness of 28 which fell well outside the required kurtosis and square of skewness region of either the negative binomial (represented by the grey region), or the poisson distributions (represented by the dashed line). Further to this,

when bootstrapping 50 observations from the data (represented by the yellow circles), none of these values fell in the required region for either of the discrete distributions .When computing the Chi-squared test the fit of the negative binomial and poisson distribution to the data, the corresponding p-values of p <0.001 similarly indicated that the data was unlikely to follow either of these distributions (Table 19).

Table 19-Fit of Yearly ED Count Data to Statistical Distributions

Distribution (Yearly ED Count Data)	Chi-squared Statistic	Chi-squared p-value	AIC	Evidence to suggest good fit	Vuong Test Statistic	Vuong Test p-value	Evidence to suggest Power-law provides better fit
Poisson	33,823.94	<0.001	771,183.6	No	5.007	<0.001	Yes
Negative Binomial	33,804.52	<0.001	771,185.6	No	-	-	-
Discrete Exponential	-	-	-	-	2.574	0.01	Yes
Discrete Lognormal	-	-	-	-	-0.536	0.592	No (equivalent)

7.5.3 Examining the Underlying Yearly ED Count Heavy-tail Distributions

7.5.3.1 Visual representation of the underlying distribution

Figure 9 shows the log-log CCDF of the number of attendances individuals make in a year. This CCDF plot indicated that the underlying distribution of an individual's yearly ED attendance count was more likely to fit heavy-tailed distributions, such as the discrete power law and discrete lognormal distributions than the poisson or discrete exponential distribution.

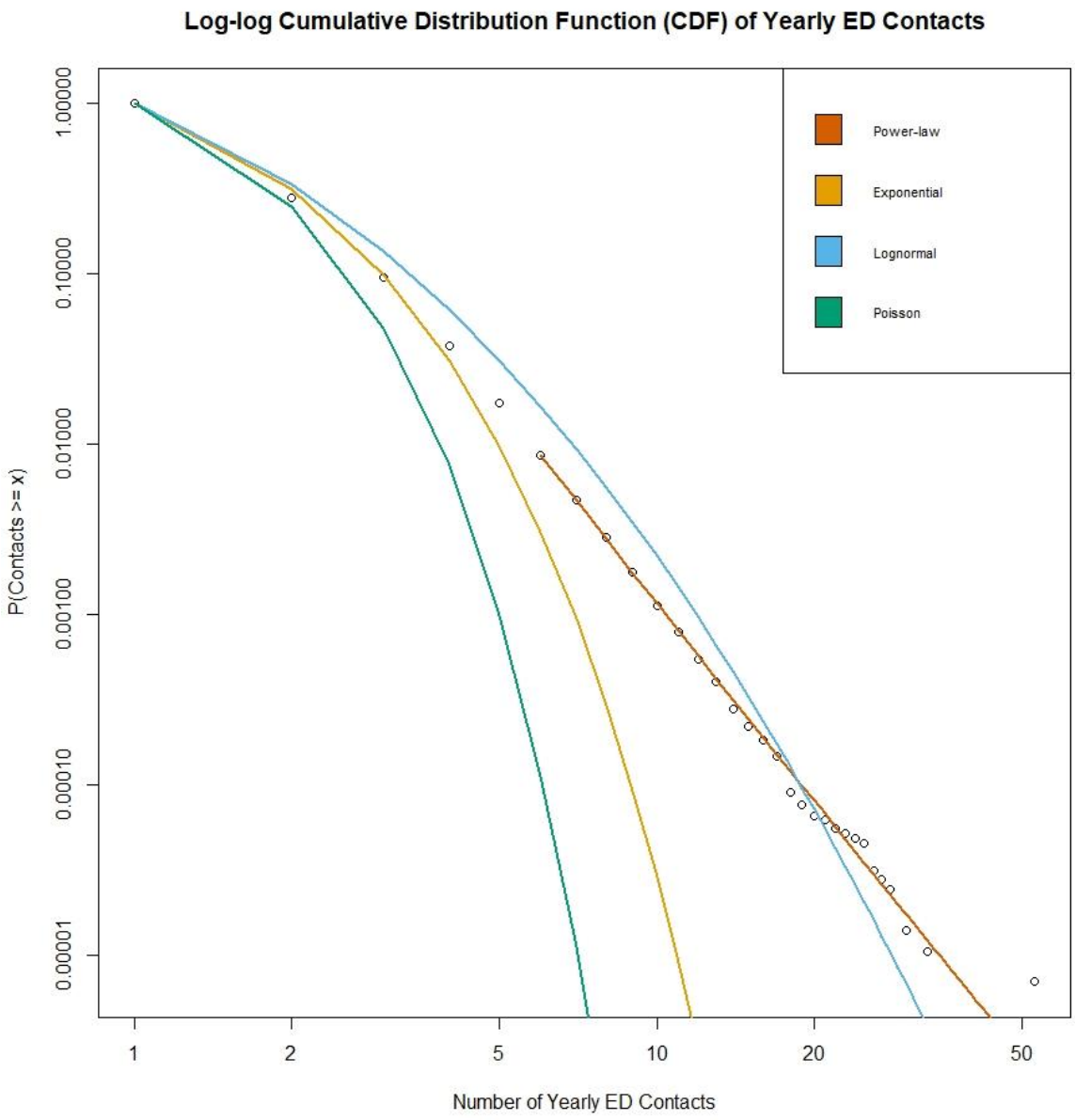

Figure 9-Plot of Complementary Cumulative Distribution Function and Statistical Distributions (log-scale)

7.5.3.2 Kolmogorov-Smirnov Goodness-of-fit Hypothesis Test

When considering the attendance distributions, the Kolmogorov-Smirnov statistic yielded a p-value of 0.6 indicating there was strong evidence ($p>0.05$) to suggest the data was likely to follow a discrete power law distribution.

7.5.3.3 Likelihood Ratio Test to Compare Fit of Data to Alternative Distributions

Although the poisson and discrete exponential distribution could be ruled out as the underlying distribution for this attendance data, the likelihood ratio test indicated that neither the discrete power law or discrete lognormal could be favoured over each other. Hence, the yearly ED attendance count distribution was likely to be heavy-tailed, with a discrete power-law and lognormal distributions providing an equally good fit to the data (see Table 19).

7.5.4 Modelling Yearly ED Count Data Using Generalised Linear Models (GLMs)

Although the yearly ED attendance data is likely to follow a heavy tail distribution such as the discrete power law or lognormal distribution, computing easily interpretable multivariable regression analyses using these distributions is not currently possible to our knowledge. Hence, considering the best fitting GLM is beneficial to ensure factors associated with high frequency ED use can still be computed. Of the four count GLMs considered (poisson, negative binomial, zero truncated poisson and zero truncated one inflated poisson models), the model with the lowest AIC was the zero truncated one inflated poisson regression model with an AIC of 492,654. The zero truncated poisson regression model was the next best fitting model with an AIC of 511,828, whereas the standard poisson and negative binomial provided the highest AIC figure (AIC=717,377) and (AIC=717,383) respectively indicating these distributions provided the worst fit of the GLMs considered. Hence the zero truncated, and zero truncated one inflated poisson regression models provided the best fit to the ED attendance count data. All computed models similarly suggested age was associated with higher rates of ED use, with individuals <1 being more likely to have higher rates of attendance than 15-17 year olds (see Table 20).

Table 20-Generalised Linear Models and Incidence Rate Ratios

	Logistic Regression		Negative Binomial Regression		Poisson Regression		Zero-Truncated Poisson Regression		Zero-Truncated One-Inflated Poisson Regression	
Predictors	OR	CI	IRR	CI	IRR	CI	IRR	CI	IRR	CI
Age										
15-17 (REF)			1	1.00-1.00	1	1.00-1.00	1	1.00-1.00	1	1.00-1.00
<1	1.88	1.79-1.97	1.17	1.16-1.18	1.17	1.16-1.18	1.46	1.41-1.46	1.35	1.31-1.39
1-4	1.12	1.07-1.16	1.01	1.00-1.02	1.01	1.00-1.02	1.04	1.02-1.06	1.03	1.01-1.05
5-9	0.69	0.66-0.72	0.92	0.91-0.93	0.92	0.91-0.93	0.75	0.73-0.76	0.69	0.68-0.70
10-14	0.99	0.94-1.03	0.99	0.98-1.00	0.99	0.98-1.00	0.97	0.95-0.98	0.86	0.82-0.89
AIC	170,488		720,877		720,870		514,799		492,654	
BIC	170,541		720,950		720,933		514,862		492,864	

7.5.5 Fitting A Count Quantile Regression Model

As we have evidence to suggest this data likely follows heavy-tail distributions, quantile regression can be used in combination with the zero truncated or zero truncated one inflated poisson regression model to provide additional information regarding the individuals making the greatest number of ED attendances. In this analysis, young age (<1) was shown to be associated with higher rates of ED attendance (using GLMs) and the quantile regression suggests a similar result when modelling median. However, quantile regression provides additional information suggesting the ED attendance rates in those making the most attendances are likely to be associated with both the youngest and oldest C&YP (see Table 21).

Table 21-Coefficients for Quantile Regression (Age=Independent Variable)

Coefficient	Estimated Coefficients & Corresponding CI (Quantiles)									
	Q(0.50)	CI	Q(0.90)	CI	Q(0.97)	95% CI	Q(0.99)	95% CI	Q(0.997)	95% CI
Age (REF=15-17)	0	-	0	-	0	-	0	-	0	-
Age (<1)	0.1	[0.093,0.11]	0.29	[0.27, 0.30]	0.23	[0.19,0.26]	0.17	[0.12,0.22]	0.078	[0.0017,0.15]
Age (1-4)	0.023	[0.019, 0.028]	0.04	[0.022, 0.053]	-0.021	[-0.048, 0.0063]	-0.11	[-0.15, -0.067]	-0.20	[-0.27, -0.14]
Age (5-9)	-0.033	[-0.037, -0.028]	-0.1	[-0.11, -0.087]	-0.021	[-0.24, -0.19]	-0.29	[-0.33, -0.25]	-0.38	[-0.45, -0.32]
Age (10-14)	0.007	[0.002,0.012]	-0.001	[-0.015,0.013]	-0.034	[-0.063,-0.0051]	-0.09	[-0.13,-0.047]	-0.19	[-0.26,-0.12]

7.6 Discussion

7.6.1 Summary of Principal Findings

This analysis has provided evidence to suggest that the number of yearly ED attendances made by C&YP are likely to follow a heavy tail distribution such as the discrete power law or lognormal distribution. This study proposes the use of a zero truncated or one inflated zero truncated poisson model in combination with a quantile count regression to analyse this in C&YP.

7.6.2 Strengths and Limitations

Due the relatively large sample of data available in the CUREd research database, this meant the underlying distribution of ED attendances made by C&YP could be examined in a whole region for this study. Although a number of studies usually use binary logistic regression to determine predictors of high frequency ED attenders (odds ratios), methods of comparing logistic and count-GLMs were not considered in this study. Hence future research may wish to produce a method of including these GLMs in the comparison of count-GLMs. Additionally, this study did not include methods such as lognormal or weighted least squares regression.

Although it may seem contradictory to suggest the use of an adapted poisson regression model after suggesting the data was unlikely to follow a poisson distribution, the motivation behind this was to find the best fitting model for the bulk of the ED attendance count data, whilst using quantile regression to help provide information regarding the tail of the distribution. This is because the poisson model is likely to omit data in the upper tail of the distribution. Although the data used in this study was from a large region of the UK,

exploring the underlying distribution of ED attendances nationwide would be beneficial. Further to this, as the CUREd database only contains data for ED attendances made prior to 2017 more up-to-date data could explore this distribution both during, and after the Covid-19 pandemic.

7.6.3 Comparison with other Studies

This study found that the yearly ED contacts made by C&YP is likely to follow a heavy-tail distribution, this is analogous to other studies assessing the use of EDs by adults.[55] The study extended their findings to suggest that the UEC system (in relation to adults) shows characteristics of a complex system. Hence, as our findings may also indicate that the UEC system (in relation to C&YP) also shows characteristics of a complex system. To our knowledge, no other studies explore the underlying distribution of yearly ED attendances with specific focus on comparing GLMs for determining the factors associated with high frequency ED use.

7.6.4 Implications for Practice and Further Research

This study has provided evidence to suggest that a zero truncated or one inflated zero truncated poisson model can be used in combination with quantile regression to assess predictors of high frequency ED use. Hence, future research may choose to use this technique to provide useful insights into high frequency use whilst maintaining the simplicity in implementation and interpretability of a GLM. The addition of quantile regression can assist exploration into the tails of ED attendance count distributions thus providing insights into extremely high frequency ED users.

7.6.5 Conclusion

Although the distribution of an individual's yearly ED use is likely to follow a heavy tail distribution such as the power law or lognormal distribution, this study has shown that when exploring factors associated with high frequency use, an adapted poisson regression model (zero truncated and one inflated zero truncated) can be used in combination with a quantile regression model to explore this.

7.7 Chapter Summary

This chapter has provided evidence to suggest the number of ED attendances made by C&YP in the Yorkshire and Humber region of the UK likely follows a heavy tail distribution such as the discrete power law distribution. This chapter then used this information to test and suggest the use of a zero truncated poisson or zero truncated one inflated poisson distribution in combination with a quantile regression model. This provides a method of assessing factors associated with high frequency ED use without needing to categorise individuals into high frequency attenders based on an arbitrary threshold. Although this dichotomous approach can be useful to find basic characteristics of frequent attending individuals, universal use of this regression technique enables a comparison of results across studies.

8 Exploring Factors Associated with High frequency Emergency Department Attendance by Children & Young People: A Retrospective Cohort Study

In preparation for publication to Emergency Medicine Journal

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8.1 Chapter Outline

In the previous section we showed that the number of ED attendances C&YP made in a year likely follows a heavy tail statistical distribution such as a power law distribution. The previous study therefore recommended the use of a modified poisson regression model in combination with a quantile regression model when assessing factors associated with the rates of attendance in C&YP. The motivation behind this study was to apply these two models to ED attendance data for C&YP to examine independent variables such as the age, sex, ethnicity and deprivation status of an individual. This was driven by evidence gaps highlighted in the systematic review produced in this PhD, which demonstrated the necessity to examine high frequency ED use in C&YP in smaller regions within the UK. Additionally, the high frequency attender systematic review also suggested that ethnicity may be associated with high frequency ED use. Hence, we included the ethnicity of an individual in our analysis to determine if this association was still found when also considering confounding factors such as deprivation in the diverse Yorkshire and Humber region of the UK.

8.2 Abstract

Background The reasons behind why children and young people (C&YP) make multiple attendances at emergency departments (EDs) represents a complex interplay of medical, socioeconomic and parental/caregiver decision making factors. Few studies have directly explored socioeconomic factors such as deprivation when considering high frequency ED use, especially within the UK setting.

Objective To explore high frequency ED use by C&YP, with additional emphasis placed on those attending EDs the most often.

Methods A retrospective cohort study was carried out of C&YP (≤17) attending an ED in the Yorkshire & Humber region of the UK between March 2016 and April 2017. Factors associated with high frequency ED use were explored using modified poisson regression to assess the association between sex, age, ethnicity and deprivation status on rates of attendance. A quantile regression model (for count data) was fit to specifically explore the association of the above patient characteristics in those making the most attendances.

Results Of the 288,545 distinct C&YP making at least one attendance to an ED, 27,560 (9.6%) were defined as high frequency ED attenders (making 3+ attendances in the year) and were responsible for 105,063 (25%) ED attendances in the study period. Frequent attending individuals were more likely to be admitted and attend via ambulance, but no more likely to be referred by a GP in comparison to occasional attenders. When considering factors associated with ED attendance rates in ED users, younger age groups and greater levels of deprivation were found to be associated with higher rates of attendance. This association was amplified in those attending the ED most often.

Conclusions The findings of this study have highlighted the need for a multifaceted approach which targets age/condition specific interventions for parent and caregivers, improved access to primary care services and the social determinants that contribute to higher ED use in more deprived areas.

8.3 Background

Visits to hospital-based services such as emergency departments (EDs) have increased in recent years, with frequent and unscheduled attendances rising by 25% in the decade prior to the covid-19 pandemic in England.[128] Due to the potential consequences of the unsustainable rise in ED use on resources and patient care, there has been notable interest amongst researchers to explore high frequency ED use.[141] While there is no universally accepted threshold for identifying high frequency ED attenders, studies generally define them as individuals who make more than 4 ED attendances within a specified timeframe-typically a year.[81] The reasons behind why individuals frequently attend ED represents a complex interplay of medical, socioeconomic, psychological and healthcare system factors.[103] When considering children and young people (C&YP) in particular, this is further complicated by parental/caregiver decision-making, which encompasses important considerations such as the perceived urgency of the child's healthcare need, but also comprises other factors such as perceived ED advantages (including faster service, superior ED resources and efficiency), convenience, and lack of access to primary care services.[142 29] Medical factors play an important role in high frequency ED use, as a study found that frequently attending C&YP were more likely to be younger children suffering from one or more chronic conditions, attending for reasons such as upper respiratory tract infections, viral infections and gastroenteritis.[81] A published systematic review outlining characteristics of frequently attending C&YP found that high frequency attenders were also more likely to be high frequency users of primary care services with factors such as deprivation being likely associated with high frequency ED use in C&YP.[92, 100, 101, 103] However, this was generally examined through the use of medical insurance with only one study exploring this in the UK.[87] The UK based study suggested that further information could be provided by analysing smaller regions of the UK to

explore more granular data, such as ED outcomes.[87] When considering high frequency ED attendance in adults, previous studies have outlined the heavy tailed nature of the ED attendance distribution.[55] This means that although a large proportion of individuals make a small number of attendances in a year period, a small proportion of individuals make a large number of ED attendances in a year. In section 7, this hypothesis was tested with C&YP, and a similar heavy tail distribution was found. This study aimed to assess the relationships between the rates ED attendance and patient characteristics, with additional emphasis placed on exploring factors associated with ED attendances in individuals attending ED the most often.

The objective of this study is to examine:

- Factors associated with rates of ED attendance in C&YP, with additional emphasis placed on those attending ED the most often.

8.4 Methods

8.4.1 Study Design

Retrospective cohort study.

8.4.2 Patient And Public Involvement

Patients were not directly involved in the planning or execution of this research which involved routinely collected healthcare data.

8.4.3 Competing Interest

No competing interest.

8.4.4 Research Ethics Approval: Human Participation

No human participation in this study.

8.4.5 Data Used

This study used data collected from the "Connected Health Cities: Data linkage of urgent care data" study (known as the "CUREd research database").[130] The CUREd Database has approval from the National Health Service (NHS) Research and Ethics Committee, overseen by the NHS Health Research Authority's Research Ethics Service, and from the NHS Health Research Authority (HRA), directly, to receive health and social care data without patient consent for patients of UEC services in Yorkshire and Humber. The CUREd research database holds data

from NHS 111 calls, emergency ambulance incidents, ED attendances and emergency admissions to hospitals in the Yorkshire and Humber region of the UK and contains an anonymised patient identifier code to facilitate linkages across the datasets. This study extracted data from the ED dataset which contained patient records between April 2016 and March 2017 (consisting of items mandated by the national Commissioning Dataset-CDS) for attendances made to the 13 participating Hospital Trusts' EDs. An ED attendance was defined as an unplanned ED attendance made to a type 1 ED, type 2 ED or other type of ED with designated accommodation for the reception of ED patients. Attendances made to services that were mainly/entirely appointment based were excluded from this analysis.

8.4.6 Data Management

8.4.6.1 Data Extraction

From the ED attendance dataset the following items were extracted: Anonymised patient identifier, encrypted attendance record identifier, sex of the patient, ethnicity of the patient, age at each attendance, attendance disposal, arrival date/time, conclusion time, low acuity attendance indicator and a patient's incident index of multiple deprivation (IMD). The distribution of patients by IMD quintiles in the data was not even; this reflects both the demography of Yorkshire and Humber generally – with more people living in deprived areas than the English average and greater ED use by people of lower sociodemographic status.

8.4.6.2 Data Preparation

Age was based on the first attendance and categorised into the following groups to align with previously published research: <1, 1-4, 5-9, 10-14 and 15-17. An ED attendance count variable was derived by aggregating the number of ED attendances an individual made to any ED in the Yorkshire and Humber region within the year study period. When examining the <1 age group, the calculated outcomes (such as Incidence Rate Ratios-IRRs) may tend to underestimate the actual values. This is because these individuals may not have had the chance to visit the ED, due to being born later in the study period. The data extraction, preparation and statistical analyses were carried using R 4.2.1 (R Software Foundation).

8.4.7 Definitions

8.4.7.1 High Frequency ED Attender

When summarising the patient and ED attendance characteristics, a high frequency ED attender was defined as an individual making 3 or more ED attendances in a year period, otherwise they were defined as an occasional attender. This was chosen because the Leeds Safeguarding Children Board use a threshold of 3 ED attendances to define high frequency attendance.[49]

8.4.7.2 Attendance Acuity

A low acuity ED attendance field was defined as an attendance made to a type 1 ED meeting the following 3 conditions [133]:

•Attendance produced at least one of the following investigation codes: None, urinalysis, pregnancy test or dental investigation

•Attendance produced at least one of the following treatment codes: Prescription(s), guidance/advice only, recording vital signs, dental treatment or no investigation

•Attendance produced at least one of the following disposals: Discharged (following treatment to be provided by GP/no follow up treatment required) or left department before being treated.

A high acuity ED attendance was defined as an attendance that resulted in the patient being admitted into hospital, and an intermediate acuity ED attendance was defined as an attendance not falling in the low or high acuity attendance category.

8.4.8 Statistical Analysis

8.4.8.1 Factors Associated with ED Attendance Rates

We found that the yearly ED attendances made by C&YP likely followed a heavy tail distribution (such as a discrete power law). We therefore used a zero truncated poisson regression model to determine factors associated with ED use for the bulk of the data, in combination with a quantile regression model to determine factors associated with ED use for those attending most often.15 A logistic regression model was also fit to determine the odds of an individual being a frequent attender using the binary definition of frequent attendance (3+ attendances in the year). The zero truncated poisson model was chosen after comparing the fit of a number of count-Generalised Linear Regression Models (count-GLMs) and was deemed appropriate due the strictly positive nature of the ED attendance count measure (as individuals made one or more yearly attendances). Quantile regression (for count data) was used to assess the association between patient factors and ED attendance rates specifically for individuals belonging to the upper tail of the attendance distribution. As we were interested in exploring individuals attending ED the most often, the 90th, 92nd, 94th, 96th, 98th, 99th, 99.5th and 99.9th quantiles were chosen in addition to the median for reference. The patient's sex, age, ethnicity and deprivation status were independent variables considered in all statistical analyses. An interaction term between ethnicity and deprivation was also evaluated in the poisson and logistic regression analyses. The resulting Incidence Rate Ratios (IRRs), Odds Ratios (ORs) and corresponding 95% confidence intervals (CI) were reported.

8.4.8.2 Sensitivity Analysis

A sensitivity analysis was conducted by computing the zero truncated poisson and quantile regression for the same data over the previous year (March 2015-April 2016).

8.5 Results

8.5.1 Patient Characteristics

In the period April 2016-March 2017, 420,051 ED attendances were made to hospitals in the Yorkshire and Humber region of the UK by 288,545 distinct C&YP. Of these individuals, 27,560 (9.6%) were defined as high frequency ED attenders (making 3+ attendances in the year) and were responsible for 105,063 (25%) ED attendances in the study period. High frequency attenders were more likely to be younger children, with 4,732 (17.2%) being under the age of 1 at the time of their first attendance, in comparison to 24,307 (9.3%) occasional ED attenders belonging to the same age group. When considering the deprivation status of an individual, high frequency attenders were more likely to belong to the more deprived groups than occasional attenders, and less likely to belong to the least deprived group. Patient ethnicity was found to be relatively similar across occasional and high frequency ED attenders in this cohort (see Table 22)

.

Table 22-Patient Characteristics for Occasional and High Frequency Users

Characteristics	Occasional ED Users (<3) N= 260,985 (90.4%)		High Frequency ED Users (≥3) N= 27,560 (9.6%)	
	n	%	n	%
Sex				
Male	143,121	54.8	15,332	55.6
Female	117,853	45.2	12,228	44.4
Missing	11	0.004		-
Age Group				
<1	24,307	9.3	4,732	17.2
1-4	69,144	26.5	8,009	29
5-9	57,996	22.2	4,140	15
10-14	58,457	22.4	5,987	21.7
15-17	33,329	12.8	3,460	12.6
Missing	17,753	6.8	1232	4.5
Ethnicity				
White	191,825	73.5	20,404	74
Asian	29,668	11.4	3,556	12.9
Black	4,020	1.5	442	1.6
Mixed Ethnicity	7,531	2.9	997	3.6
Other Ethnicities	7,811	3	1,009	3.7
Missing	20,130	7	1,152	4.2
IMD Status				
1 (Most Deprived)	108,737	41.7	13,415	48.7
2	46,969	18	4,996	18.1
3	37,162	14.2	3,626	13.3
4	37,472	14.4	3,200	11.6
5 (Least Deprived)	29,148	11.2	2,282	8.3
Missing	1,497	0.6	41	0.1

8.5.2 Attendance Characteristics

When considering ED attendances made by high frequency attenders, a greater proportion were defined as high acuity (17,917, 17.1%) in comparison to attendances made by occasional attenders (36,951, 11.7%). High frequency attenders were similarly likely to have been referred

to an ED by a GP in comparison to occasional attenders and were marginally more likely to arrive by ambulance (see Table 23).

Table 23-ED Attendance Characteristics for Occasional and High Frequency Users

Characteristics	Attendances Made by Occasional ED Users (<3) N=314,988		Attendances Made by High Frequency ED Users (≥3) N=105,063	
	n	%	n	%
Acuity				
Low Acuity	59,709	19	19,062	18.1
Intermediate Acuity	173,509	55.1	49,083	46.7
High Acuity	36,951	11.7	17,917	17.1
Missing	44,819	14.2	19,001	18.1
Referral				
GP	38,941	12.4	14,256	13.5
Self	227,124	72.1	76,031	72.4
Other/Missing	48,923	15.5	14,776	14.1
Arrival Mode				
Ambulance	34,897	11.1	14,367	13.7
Other	272,592	86.5	88,630	84.4
Missing	7,499	2.4	2,066	1.9

8.5.3 Factors Associated with High Frequency ED Use

Table 24 displays the results of the zero truncated poisson regression. This shows a U-shaped relationship between age and yearly ED attendance rates, with the IRR highest in children under 1 (IRR=1.40, 95% CI=1.38-1.43) at the time of their first attendance and lowest in children aged 5-9 (IRR=0.73, 95% CI=0.72-0.74), in comparison to individuals aged 15-17. Those belonging to the most deprived category were found to have the highest IRR in comparison to those belonging to the least deprived groups (IRR=1.30, 95% CI=1.27-1.33). This meant that those belonging to the most deprived groups were more likely to have higher rates of attendance than

those belonging to the least deprived groups. An association was found between Mixed Ethnicity (IRR=1.07, 95% CI=1.04-1.10) and Other Ethnicities (IRR=1.10, 95% CI=1.07-1.13) implying these ethnicities had higher rates of ED attendance than White individuals. In addition to this, Black Ethnicity (IRR=0.95, 95% CI=0.91-0.99) was associated with lower rates of ED attendances in comparison to White individuals. However there was no statistically significant association found between Asian ethnicities (IRR=1.01, 95% CI=0.99-1.03) and rates of ED attendance in comparison to White individuals. The interaction between an individual's deprivation and ethnic status generally displayed lower rates of attendance for ethnic minorities belonging to the most deprived category. However, this was not seen in Black patients (See Table 24). There was a small but statistically significant association between the sex of an individual and the rates of attendance (IRR=0.98, 95% CI=0.97-0.99).

Table 24-Zero-Truncated Poisson Regression Model Incidence Rate Ratios

	Logistic Regression		ZT Poisson Regression	
Predictors	OR	95% CI	IRR	95% CI
Sex				
Male (REF)	1.00	1.00-1.00	1.00	1.00-1.00
Female	0.98	0.97-0.99	0.98	0.97-0.99
Age				
15-17	1.00	1.00-1.00	1.00	1.00-1.00
10-14	0.96	0.94-0.97	0.96	0.94-0.97
5-9 (REF)	0.73	0.72-0.74	0.73	0.72-0.74
1-4	1.00	0.98-1.01	1.00	0.98-1.01
<1	1.40	1.38-1.43	1.40	1.38-1.43
Deprivation				
5 (Least Deprived, REF)	1.00	1.00-1.00	1.00	1.00-1.00
4	1.04	1.02-1.07	1.04	1.02-1.07
3	1.12	1.09-1.15	1.12	1.09-1.15
2	1.20	1.17-1.23	1.20	1.17-1.23
1 (Most Deprived)	1.30	1.27-1.33	1.30	1.27-1.33
Ethnicity Group				
White (REF)	1.00	1.00-1.00	1.00	1.00-1.00

Asian	1.01	0.99-1.03	1.01	0.99-1.03
Black	0.95	0.91-0.99	0.95	0.91-0.99
Mixed	1.07	1.04-1.10	1.07	1.04-1.10
Other	1.10	1.07-1.13	1.10	1.07-1.13
Ethnicity/Deprivation Interaction				
Deprivation [1] & Asian	**0.79**	**0.62 – 1.02**	**0.82**	**0.74 – 0.90**
Deprivation [2] & Asian	0.86	0.67 – 1.12	0.87	0.78 – 0.97
Deprivation [3] & Asian	1.04	0.79 – 1.38	0.95	0.85 – 1.06
Deprivation [4] & Asian	0.88	0.65 – 1.21	0.93	0.82 – 1.05
Deprivation [1] & Black	**0.94**	**0.48 – 2.13**	**1.03**	**0.76 – 1.41**
Deprivation [2] & Black	0.92	0.44 – 2.15	0.99	0.71 – 1.37
Deprivation [3] & Black	1.03	0.46 – 2.51	1.01	0.70 – 1.44
Deprivation [4] & Black	1.20	0.48 – 3.16	1.40	0.96 – 2.03
Deprivation [1] & Mixed	**0.83**	**0.62 – 1.12**	**0.86**	**0.76 – 0.97**
Deprivation [2] & Mixed	0.89	0.65 – 1.24	0.93	0.81 – 1.06

Deprivation [3] & Mixed	0.89	0.63 – 1.27	0.86	0.75 – 1.00
Deprivation [4] & Mixed	0.80	0.55 – 1.16	0.82	0.71 – 0.96
Deprivation [1] & Other Ethnicities	**0.82**	**0.61 – 1.14**	**0.85**	**0.75 – 0.96**
Deprivation [2] & Other Ethnicities	0.86	0.61 – 1.24	0.91	0.79 – 1.05
Deprivation [3] & Other Ethnicities	0.97	0.67 – 1.44	0.91	0.78 – 1.07
Deprivation [4] & Other Ethnicities	0.60	0.38 – 0.95	0.80	0.67 – 0.95
N=268,276				

8.5.3.1 Factors Associated with ED Attendance Rates in those Attending Most Often

Table 25 shows the coefficients of the quantile regression model and demonstrates the U shape relationship between age and ED attendance rates becomes deeper for those attending most often. Specifically, both those under the age of one and those aged 15-17 were more likely to be associated with higher rates of ED attendances in those attending the most often. Higher levels of deprivation were found to have a greater effect on ED attendance rates in those who attend the most. However, although there was a small but statistically significant association between Other Ethnicities and rates of attendance when considering those who attended the most, there was little or no correlation between the ethnicity of an individual and ED use when modelling these individuals (see Table 25).

8.5.4 Sensitivity Analysis

The results a sensitivity analysis (conducted using 2015-2016 data) were found to be analogous to the findings outlined in the results in the main analysis and are presented in the Appendix (see Table 29 and Table 30).

Table 25-Coefficients for Quantile Regression

Coefficient	Estimated Coefficients & Corresponding 95% CI (Quantiles)									
	Q(0.50)	CI	Q(0.90)	CI	Q(0.97)	95% CI	Q(0.99)	95% CI	Q(0.997)	95% CI
Age										
REF=15-17	0	-	0	-	0	-	0	-	0	-
10-14	0.01	[0.001, 0.01]	-0.005	[-0.02, 0.01]	-0.04	[-0.07,-0.01]	-0.10	[-0.14, -0.06]	-0.20	[-0.27, -0.12]
5-9	-0.04	[-0.04, -0.03]	-0.12	[-0.13, -0.10]	-0.23	[-0.25, -0.20]	-0.30	[-0.35, -0.27]	-0.40	[-0.48, -0.34]
1-4	0.02	[0.01, 0.02]	0.03	[0.01, 0.05]	-0.04	[-0.06, -0.01]	-0.13	[-0.17, -0.10]	-0.24	[-0.31, -0.18]
<1	0.09	[0.09, 0.10]	0.27	[0.25, 0.29]	0.20	[0.18, 0.24]	0.14	[0.09, 0.19]	0.07	[-0.03, 0.12]
Deprivation										
5 (Least Deprived, REF)	0	-	0	-	0	-	0	-	0	-
4	0.005	[-0.0001, 0.1]	0.01	[0.0003, 0.03]	0.03	[0.003, 0.06]	0.04	[-0.002, 0.09]	0.08	[0.008, 0.15]
3	0.02	[0.01, 0.02]	0.05	[0.03, 0.06]	0.08	[0.05, 0.11]	0.08	[0.03, 0.12]	0.15	[0.07, 0.22]
2	0.03	[0.02, 0.04]	0.07	[0.06, 0.09]	0.13	[0.10, 0.16]	0.14	[0.10, 0.18]	0.21	[0.14, 0.27]
1 (Most Deprived)	0.04	[0.04, 0.05]	0.13	[0.12, 0.14]	0.18	[0.16, 0.21]	0.17	[0.14, 0.21]	0.22	[0.16, 0.28]
Ethnicity Group										
White (REF)	0	-	0	-	0	-	0	-	0	-
Asian	0.001	[-0.003, 0.006]	0.01	[-0.003, 0.03]	0.02	[0.003, 0.05]	0.04	[-0.003, 0.07]	0.02	[-0.03, 0.07]
Black	-0.01	[-0.02, 0.003]	-0.03	[-0.07, 0.003]	-0.04	[-0.09, 0.01]	0.02	[-0.12, 0.16]	0.02	[-0.2, 0.07]
Mixed	0.01	[0.005, 0.02]	0.05	[0.02, 0.08]	0.06	[0.02, 0.09]	0.05	[-0.03, 0.12]	0.04	[-0.08, 0.16]
Other	0.01	[0.005, 0.02]	0.04	[0.02, 0.07]	0.09	[0.05, 0.13]	0.13	[0.073, 0.19]	0.11	[0.02, 0.20]

8.6 Discussion

8.6.1 Summary of Principal Findings

A relatively small proportion of C&YP were defined as high frequency ED attenders (27,560, 9.6%) but were responsible for a relatively large proportion of ED attendances (105,063, 25%). High frequency attenders were more likely to be admitted to hospital after attending an ED, than occasional users. When considering factors associated with ED attendance rates in ED users, younger age groups and greater levels of deprivation were found to be associated with higher rates of attendance. This association was amplified in those attending the ED most often. Ethnicity was found to be associated with ED attendance rates, with Mixed Ethnicities and Other Ethnicities having greater rates of attendance than White individuals, and Black ethnicities having lower attendance rates in comparison to White individuals. However, with the exception of Other Ethnicities the association between ethnicity and rates of attendance diminished when considering those who attended ED the most often.

8.6.2 Strengths and Limitations

This study is the first known study to use a combination of a modified poisson regression model and a quantile regression model when considering ED attendance. This is beneficial when analysing factors associated with ED attendance rates as it removes the need to categorise individuals into high frequency attenders based on an arbitrary threshold. The quantile regression conducted in this analysis provides a more dynamic picture of high frequency attenders by

exploring quantiles of attenders based on the number of attendances they make. This enabled us to explore factors associated with ED attendance rates in those who attend the most. Due to the lack of linkable primary care data, high frequency use of primary care services could not be explored as a factor associated with high rates of ED attendance in C&YP.

8.6.3 Comparison with other Studies

Previous studies have found that younger age was associated with high frequency ED use in C&YP and this study has provided similar findings.[81] This study however has suggested that older age groups were equally likely to have high rates of attendance in comparison to other age groups when considering those who attend ED the most. One nationwide (England) study suggests ethnicity was a predictor of high frequency attendance in C&YP.[87] The study similarly found that the odds of being a high frequency attender was lower for Black Ethnicities and greater for Mixed Ethnicities in comparison to White individuals. However, the nationwide study found the odds of being a high frequency attender was higher in Asian Ethnicities and lower in Other Ethnicities in comparison to White individuals. This implies there is likely to variation in the association between ethnicity and rates of ED attendance in different regions of the UK. While in our study the presence of chronic conditions was not recorded, the findings that ED attendances made by high frequency attenders were more likely to be high acuity and arrive by ambulance, this could suggest that these individuals were more likely to have chronic conditions.

8.6.4 Implications for Practice and Further Research

This study has provided evidence to suggest the effect of factors such as age, ethnicity and deprivation levels on attendance rates are not constant across all ED users, and thus differ for those who attend ED the most. As ED clinicians have described an increase in repeated mental health presentations in older C&YP (with impacts of the Covid-19 pandemic exacerbating this problem), further research could explore this cohort in detail.[143] Although there may be some evidence to suggest that a proportion of high frequency ED attenders suffer from chronic conditions, the association between increased deprivation and higher rates of ED attendance could indicate that factors such as reduced access to other healthcare services or reduced healthcare literacy may also play a part in high frequency ED attendance. Healthcare providers should consider implementing further preventative measures and health education programs targeted at parents and caregivers of young and vulnerable children to reduce the necessity for frequent ED visits. As this study found that ethnic minorities belonging to the most deprived IMD status generally displayed lower rates of ED attendance, this highlights the need for improved access to healthcare services for ethnic minorities living in more deprived areas. Future research could explore sub-demographic factors such as the immigration status of ethnic minorities when considering ED use by C&YP.

8.6.5 Conclusion

The findings of this study have highlighted the need for a multifaceted approach which targets age/condition specific interventions for parent and caregivers, improved access to primary care services and the social determinants that contribute to higher ED use in more deprived areas.

8.7 Chapter Summary

The analysis conducted in this section found a number of factors associated with high frequency ED use in C&YP. Specifically, age was found to have a U-shaped association with rates of ED attendance, with individuals under the age of one and those aged 15-17 having greater rates of attendance. This U shape association was amplified in those attending EDs the most often. Deprivation was similarly found to be associated with high rates of ED attendance, with those belonging to the most deprived groups being more likely to attend EDs frequently. Ethnicity was found to be associated with rates of ED attendance, implying some ethnicities are being disproportionately represented at the ED. To explore high frequency use in more detail, reasons for attendance and high frequency use are explored in the next chapter.

9 Examining High Frequency Emergency Department Use and Reasons for Attendance by Children & Young People: A Retrospective Cohort Study

In preparation for publication to Emergency Medicine Journal

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9.1 Chapter Outline

The previous section outlined the importance of examining factors associated with high frequency ED use over a year period. The study in this section extends this analysis to consider two years. In particular, this study retrospectively examines ED attendances made by C&YP over two consecutive 12 month periods. The motivation behind this analysis was driven by the lack of studies exploring patterns of ED use over a two year period. In addition to this, we specifically explore medical reasons for attendance in this analysis by describing the heterogeneity of reasons for attending in those making a large number of attendances over their two year observation period. This could be a marker for safeguarding issues and has not been previously explored in C&YP.

9.2 Abstract

Background In recent years emphasis has been placed on understanding the use of urgent and emergency care (UEC) services by children and young people (C&YP) due to rises in emergency care activity in this demographic. Although studies usually analyse emergency department (ED) use by C&YP over a single year, understanding patterns of ED attendance over a 2 year period can provide equally important insights-especially for those who frequently attend EDs. In particular, exploring the heterogeneity of reasons for attendance in high frequency attenders can help identify individuals requiring support for potential safeguarding issues.

Objective To measure ED attendance patterns over a 2 year period and use ED attendance diagnostic codes to examine heterogeneity in reasons for attendance in these C&YP.

Methods We analysed data for ED attendances made over two consecutive 12 month periods (beginning with the date of the first attendance) by individuals under the age of 15 in the Yorkshire and Humber region of the UK (2015-2017). Alluvial plots were produced to show the number of ED attendances individuals made in each of their two observation years (by age and deprivation). Reasons for attendance were extracted for individuals making 7-13 attendances over their two year observation period, and a Herfindahl index computed to determine the heterogeneity of reasons for attendance in individuals. We produced boxplots and fit a linear regression model to determine the association between age and deprivation and heterogeneity of reasons for attendance.

Results We retrospectively analysed ED attendance made by 71,143 individuals under the age of 15, over a two year period. Although a relatively small proportion of individuals were defined as high frequency attenders in their first observation year (9,700, 13.6%), over half of these individuals made at least one attendance in their second observation year (5,345, 55.1%). 1,369

individuals were defined as high frequency attenders in both observation years and were more likely to belong to the most deprived IMD category. Those aged 8-12 were more likely to make injury related attendances and less likely to make illness related attendances. Conversely, those under the age of 1 were less likely to make injury related attendances and more likely to make illness related attendances. The analysis of reasons for attendance in 1,199 individuals (making 7-13 ED attendances in the observation period) found there was less heterogeneity in the reasons for attendance in those aged 8-12 in comparison to those under the age of 1.

Conclusion The heterogeneity for reasons of attendance, in combination with the number/proportion of injury or illness attendances an individual makes can be an important marker for investigating safeguarding issues.

9.3 Background

Urgent and emergency care (UEC) services such as emergency departments (EDs) have experienced huge pressure in recent years from rising demand for care.[144] To combat this, a delivery plan produced by NHS England in January 2023 set out a number of ambitions, with the overarching aim of reducing strain on UEC services.[145] The report suggests that current pressures on UEC services are likely due to factors such as the lasting impact of the COVID-19 pandemic, the consequence of population growth, an ageing population and greater number of people living with long term conditions. As part of the plan, a £250 million dedicated fund has been provided to the NHS to boost frontline capacity, including the creation of 900 new hospital beds to treat more patients in the UEC setting.[146] Also included in the plan is the proposed expansion of NHS virtual wards which aims to provide hospital-level care to a large number of children and young people (C&YP) across England from their homes, potentially relieving pressure on UEC services.[147] Specific emphasis has been placed on understanding the use of UEC services by C&YP due to recent rises in emergency care activity in this demographic, including the large number of scarlet fever and invasive group A streptococcus related ED attendances in 2022/23.[148] One study exploring healthcare use in C&YP found that whilst GP consultations generally decreased for C&YP between the years 2007/2008 and 2016/2017, ED attendance rates increased across this demographic over the same period.[149]

Exploring how and why C&YP use UEC services is important, as their healthcare needs can differ greatly from adults meaning specialist advice and support is usually required (especially for younger children who can be particularly vulnerable and dependent on their parents/caregivers).[150] When considering ED use by C&YP, most studies report attendance data from a single year, highlighting the need for research into ED use over multiple years.[151] This

can provide useful information into the ED attendance patterns of C&YP, especially for those defined as high frequency attenders. C&YP attend EDs for a wide variety of reasons, ranging from injury, to illness related attendances.[152] For frequently attending C&YP, although there is evidence to suggest these individuals were more likely to be living with one or more long term conditions [103], little is known about the heterogeneity of reasons for attending EDs. Exploring the heterogeneity of reasons for attending the ED is important to understand attendance behaviors in individuals. Specifically, C&YP making a large number of attendances for similar reasons such as injuries may need to be screened for safeguarding issues and signposted for support and help.[153]

The objective of this study is to

1. Measure C&YP's ED attendance patterns over a 2 year period.
2. Look at common reasons for ED attendances in C&YP.
3. Examine heterogeneity in reasons for attendance in C&YP.

9.4 Methods

9.4.1 Study Design

Retrospective cohort study.

9.4.2 Patient And Public Involvement

Patients were not directly involved in the planning or execution of this research which involved routinely collected healthcare data.

9.4.3 Competing Interest

No competing interest.

9.4.4 Research Ethics Approval: Human Participation

No human participation in this study.

9.4.5 Data Used

This study used data collected from the "Connected Health Cities: Data linkage of urgent care data" study (known as the "CUREd research database").[130] The CUREd Database has approval from the National Health Service (NHS) Research and Ethics Committee, overseen by the NHS Health Research Authority's Research Ethics Service, and from the NHS Health Research Authority (HRA), directly, to receive health and social care data without patient consent for patients of UEC services in Yorkshire and Humber. The CUREd research database holds data from NHS 111 calls, emergency ambulance incidents, ED attendances and emergency

admissions to hospitals in the Yorkshire and Humber region of the UK and contains an anonymised patient identifier code to facilitate linkages across the datasets. This study extracted data from the ED dataset which contained patient records between April 2014 and March 2017 (consisting of items mandated by the national Commissioning Dataset-CDS) for attendances made to the 13 participating Hospital Trusts' EDs. An ED attendance was defined as an unplanned ED attendance made to a type 1 ED, type 2 ED or other type of ED with designated accommodation for the reception of ED patients. Attendances made to services that were mainly/entirely appointment based were excluded from this analysis.

9.4.6 Data Management

9.4.6.1 Data Extraction

The data extraction, cleaning, linking and statistical analyses were performed using R 4.2.1 (R Software Foundation) and packages such as "dplyr" and "alluvial". From the ED attendance dataset the following items were extracted: Anonymised patient identifier, encrypted attendance record identifier, date/time of ED attendance, sex of patient, incident index of multiple deprivation (IMD) quintiles, age at first attendance, the hospital/ED an attendance was made to and the primary reason for attendance (primary diagnosis).

9.4.6.2 Cohort Preparation

For most EDs, rates of coding were very low. EDs were included in this analysis if they contained 70%+ non-missing primary reason for attendance codes. This resulted in four EDs being used in this study - two university teaching hospitals and two district general hospitals. We selected data from individuals (aged 15 and under) making an ED attendance to one of the above

EDs within the year March 2014-March 2015. The date of their first attendance in the year was noted. We extracted data for each attendance made over the two consecutive 12 month periods beginning with the date of the first attendance. This method was chosen to ensure the same follow-up duration for each individual. We defined a high frequency attender in a given 12 month period if the individual made 3 or more attendances in the period.

9.4.6.3 Sensitivity Analysis

Other cut-off points for missing reason for attendance codes were explored in a sensitivity analysis using a threshold of 50% and 90% respectively. For the sensitivity analysis using a 50% threshold, the proportion of missing values in the data meant some reasons for attendance were not captured. For example there were no asthma presentations to the ED in this cohort which did not align with previous literature and expert opinion. Thus this cut-off was not chosen in the final analyses. Similarly, reasons for attendance were collated for hospitals with 90% non-missing values. Unfortunately, this produced too few attendances meaning any Herfindahl calculations would display confidence intervals too large to make any statistically justifiable conclusions. Hence a threshold of 70% was chosen to use in this analysis.

9.4.6.4 Reason for Attendance

We extracted the reason for attendance (where stated) for each given ED attendance. Two different coding systems were used across the four EDs in this analysis, one using ICD-10 (International Classification of Diseases) codes and three using ECDS (Emergency Care Data Set) codes. For ECDS codes we considered 4, 5 or 6 digit codes as they provided sufficient information to determine the reason for attendance. However, codes of length 1, 2 or 3 were

omitted due to ambiguity (as these codes may have represented anatomical side and/or area). The ECDS codes grouped reasons for attendance into 26 categories. As the ICD-10 codes provided more detail regarding the reasons for attendance, these codes were grouped into 14 categories based on the ICD-10 (version 2016) disease classifications. With the assistance of medical professionals, we then mapped the ECDS codes to the ICD-10 codes and provided a new unique single letter code for each of the final categories (see appendix, for the final 14 categories and ECDS/ICD-10 codes). Attendance codes were then combined into a character string for each patient (for example an individual making 4 attendances in their observation period may have the following attendance string "AABC"). Finally, as some individuals were found to be more likely to have multiple missing reasons for attendance, individuals containing 50%+ missing values were omitted from this analysis.

9.4.7 Statistical Analysis

9.4.7.1 Exploring ED use Over a 2 Year Period

To examine the use of EDs during the two-year observation period, we categorised individuals based on the number of attendances they made in the first 12 month observation period (1, 2, or 3+ attendances). Similarly, for the second 12 month observation period, individuals were grouped based on the number of attendances they made in the second 12 month period (0, 1, 2, or 3+ attendances). Alluvial plots were then produced to visualise the number of attendances an individual made across the two observation years, by age (age categories <1, 1-4, 5-9, 10-15) and IMD status (one category for the more deprived individuals (IMD=1 or 2) and one category for less deprived individuals, (IMD=3, 4 or 5).

9.4.7.2 Exploring Reasons for Attendance

The reasons for attendance were summarised for those making 1 attendance in their 2 year observation period; those defined as a high frequency attender in both observation years; and all other individuals. The proportion of injury and illness related ED attendances made by individuals were plotted (boxplot) by age.

9.4.7.3 Heterogeneity of Reasons for ED Attendances

To quantify the heterogeneity of the reasons for attendances in the cohort of individuals, a Herfindahl index was computed for each individual.[154] The Herfindahl index provides a value between 0 and 1 and relates to the number of different attendance reasons across individuals. For a sequence of consultations including N different categories; and where P_i represents the proportion of consultations belonging to the i^{th} category:

$$Herfindahl\ index = \sum_{i=1}^{N} P_i^2$$

A value close to one indicates the patient made a large proportion of attendances for the same reason (low heterogeneity) and a value closer to zero indicates the patient made attendances for different reasons (high heterogeneity). As the values for the Herfindahl index were consistent with small numbers of attendances, we produced a plot to identify a range within which there was no relationship between the Herfindahl index and number of attendances (see appendix, Figure 18). This suggested that the Herfindahl index could be analysed for individuals making between 7 and 13 attendances within their two year observation period, as the number of attendances an individual made was unlikely to confound the Herfindahl index within this threshold. We then visualised the Herfindahl index across age and IMD status to determine the

heterogeneity of reasons for attending EDs in the cohort. A linear regression model was then computed to test the association between an individual's Herfindahl index and their characteristics (sex, age and IMD status). For this regression analysis age was categorised to <1, 1-4, 5-7, 8-12, and 13-15.

9.5 Results

9.5.1 Patient and Attendance Characteristics

The study cohort consisted of 71,143 individuals, making a total of 163,814 ED attendances. Individuals had a median of 2 attendances made across their personal two year observation period. The ED with the most attendances had 52,284 attendances (31.9%) and the ED with the least attendances had 17,686 attendances (10.8%). Table 26 shows the distribution of age, sex and IMD quintile. Of the 71,143 individuals included in this study, the majority were under the age of 4 (29,996, 42.2%) and belong to the most deprived IMD category (33,647, 47.3%).

Table 26-Patient Characteristics (Full Patient Cohort)

Characteristics	Patient Cohort N=71,143	
	n	%
Sex		
Male	39,444	55.4
Female	31,690	44.5
Missing	9	<0.1
Age Group		
<1	7,298	10.3
1-4	22,698	31.9
5-9	17,970	25.2
10-15	23,177	32.6
Missing	0	0
Ethnicity		
White	49,462	69.5
Asian	11,965	16.8
Black	409	0.7
Mixed Ethnicity	1,344	1.9
Other Ethnicities	1,602	2.2
Missing	6,361	8.9
IMD Status		
1 (Most Deprived)	33,647	47.3
2	12,740	17.9
3	8,690	12.2
4	8,626	12.1
5 (Least Deprived)	7,003	9.8
Missing	437	0.7

9.5.2 Exploring ED use Over a 2 Year Period

While all individuals in the cohort had their index attendance in the first year, 33,856 (47.6%) had no further attendance in the 2 years. On the other hand, 10,936 (15.4%) individuals had no further attendance in year 1 but had one or more attendances in year 2. A relatively small proportion of the cohort were defined as high frequency attenders (with three or more attendances) in their first observation year (9,700, 13.6%). Over half of these high frequency attenders made at least one attendance in their second year of observation (5,345, 55.1%), and a proportion were also found to be high frequency attenders in the second year of observation (1,369, 14.1%). Figure 10 and Figure 11 show the number of attendances individuals made in years 1 and 2 split by deprivation and age respectively. Individuals defined as high frequency attenders in both observation years were more likely to belong to the more deprived IMD categories 73.6% (71.2 to 76%) in comparison to those making a single attendance over the two year period 62.7% (62.2 to 63.2%). A relatively large proportion of high frequency attenders in the first observation year were under the age of 1 (1649, 17%). Of these individuals 275 (16.7%) were high frequency attenders in year 2, whereas 331 (10.6%) of frequenting attending individuals aged 1-4 in year 1 were high frequency attenders in year 2.

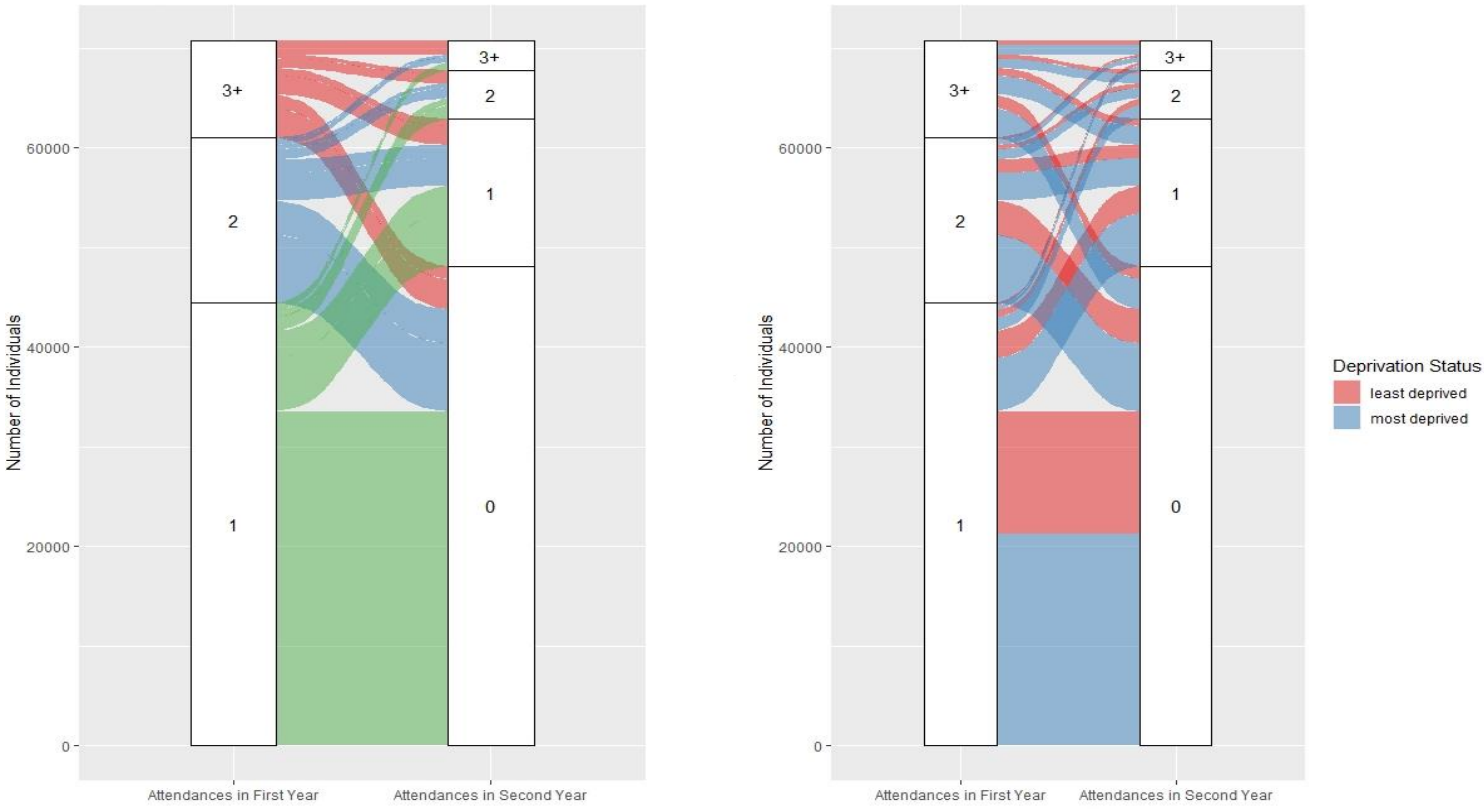


Figure 10-Number of Attendances Made in Each Observation Year by Cohort (Deprivation Status)

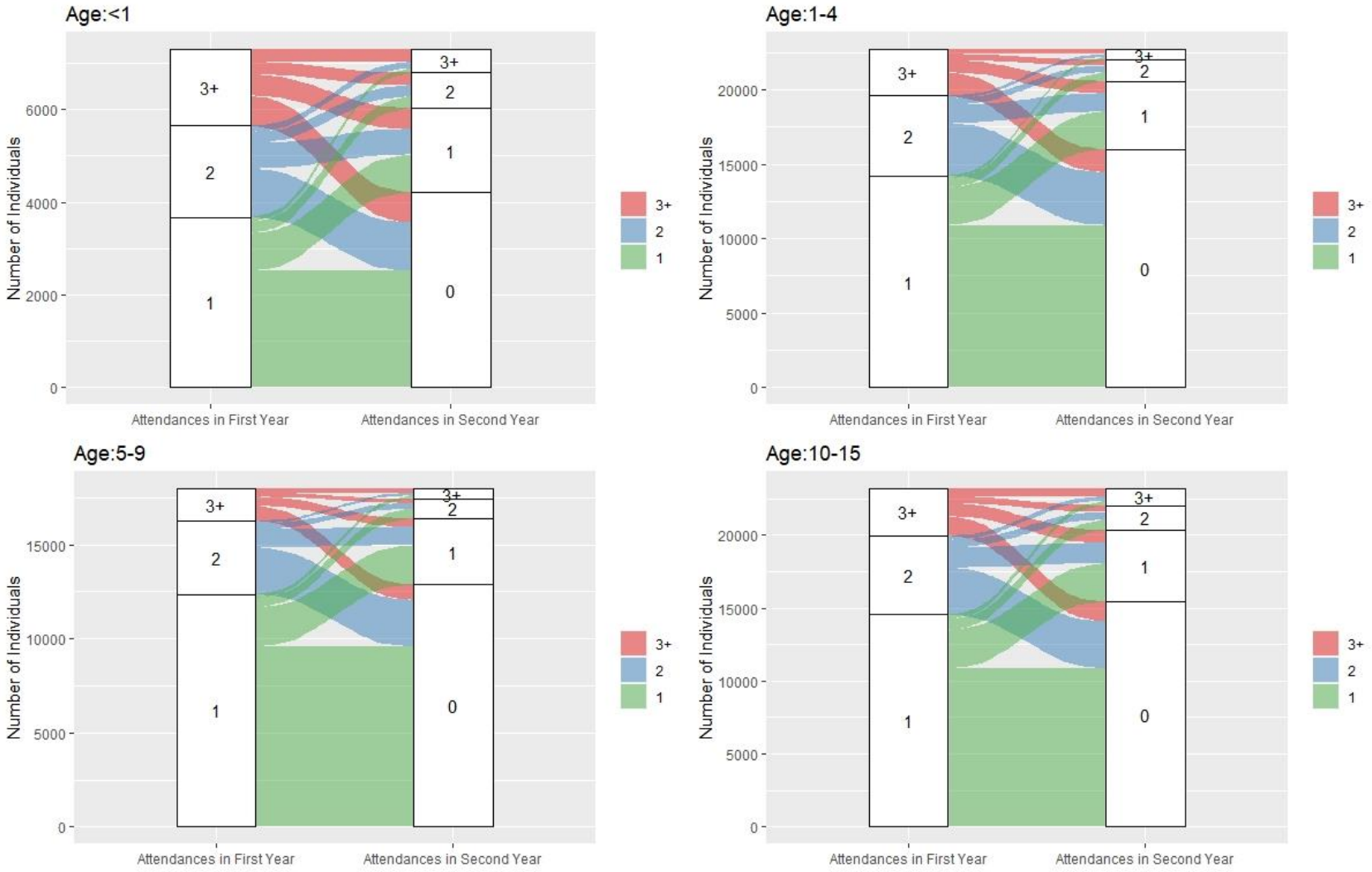


Figure 11-Number of Attendances Made in Each Observation Year by Cohort (Age)

9.5.3 Reasons for ED Attendance

The reasons for these attendances were largely split into injury and illness, with 72,155 (44%) attendances being attributed to an injury and 38,511 (23.5%) being attributed to an illness (Table 27).

Table 27-Reasons for ED Attendances in Frequent, Single and Other Attenders

Reason for Attendance	Number and Proportion of Attendances made by:						
	One-time Attenders (N=33,846)	%	Frequent Attenders in both years (N=1,369)	%	Other Attenders (N=35,928)	%	Total (N=71,143)
Injury	16,019	47.3	4,192	34.9	45,973	44	66,184
Respiratory Conditions (Non-Asthma)	1,266	3.7	1,102	9.2	6,367	6.1	8,735
Infection/infectious disease	1,178	3.5	520	4.3	4,341	4.2	6,039
Gastrointestinal Conditions	911	2.7	527	4.4	3,487	3.3	
ENT Conditions	968	2.9	347	2.9	3,542	3.4	
Central Nervous System conditions	351	1	450	3.7	1,699	1.6	
Asthma	98	0.3	161	1.3	584	0.6	
Urinary Conditions	175	0.5	61	0.5	495	0.5	
Vascular/Haematological Conditions	135	0.4	27	0.2	304	0.3	
Cardiac Conditions	70	0.2	29	0.2	260	0.2	
Mental Health	29	0.09	35	0.3	130	0.1	
Diabetes	12	0.04	16	0.1	30	0.03	
Other conditions	1,359	4	500	4.2	4,229	4.2	
Missing	11,269	33.3	4,039	33.6	32,998	32	
Total	33,846	100	12,016	100	104,469	100	

Figure 12 displays a boxplot of the proportion of ED attendances occurring due to injury and illness by age. This suggests that younger individuals were less likely to attend for injury related problems and more likely to attend for illness related problems. Conversely, older individuals were more likely to make injury related attendances and less likely to attend for illness related concerns. Injury related ED attendances were less common in those defined as high frequency attenders in both years 35% (34 to 35.8%), compared to those making a single attendance in the two year period 47.2% (46.8 to 47.9%). Illness related attendances were more common among those defined as high frequency attenders in both years 31.5% (30.7 to 32.3%) compared to those making a single attendance in the two year period 19.4% (19 to 19.8%).

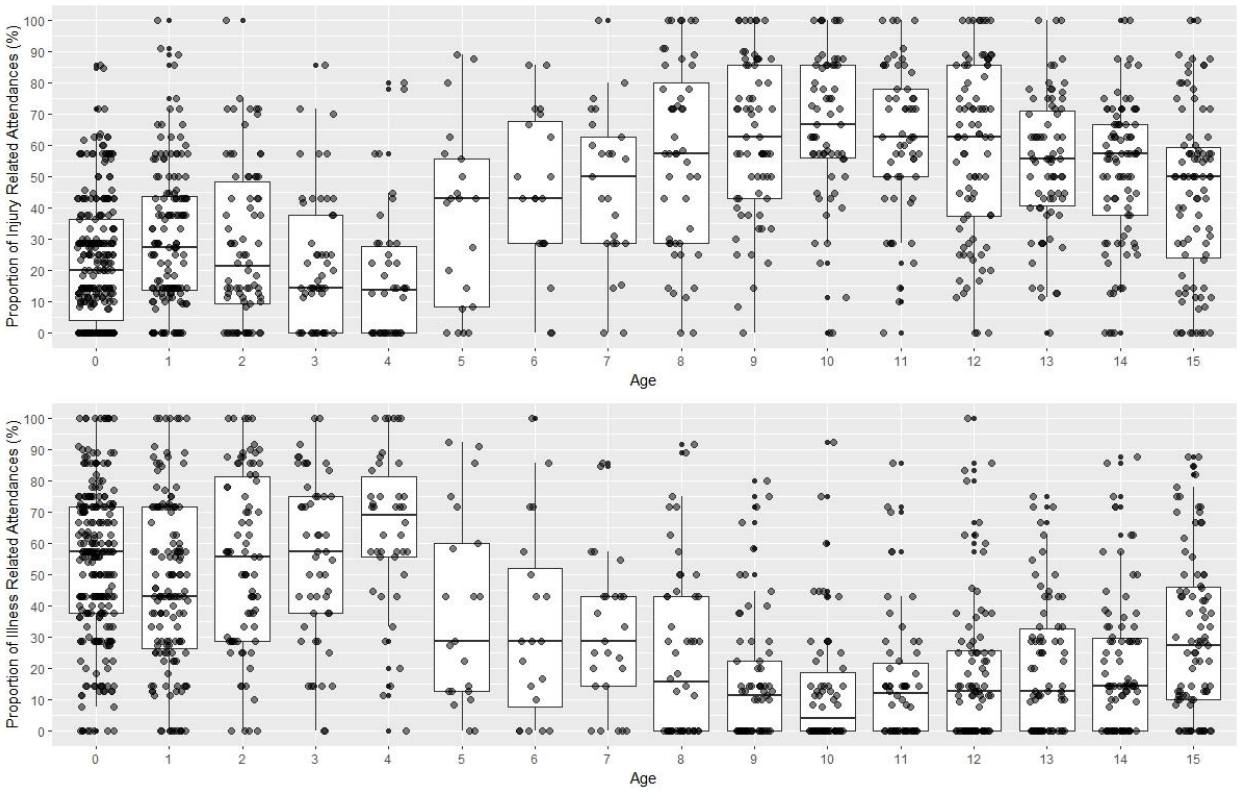


Figure 12-Proportion of Injury and Illness Related ED Attendances by Age

9.5.4 Heterogeneity of Reasons for ED Attendance

Of the 71,143 individuals, 18,098 (25.4%) were removed from the Herfindahl analysis due to them having 50% or more of their reasons for attendance missing. A further 59,686 individuals made less than 7, or more than 13 attendances over the 2 year period and were also removed from the analysis. This left 1,199 individuals for the Herfindahl index analysis. Figure 13 shows the relationship between an individual's Herfindahl index and their age/deprivation status.

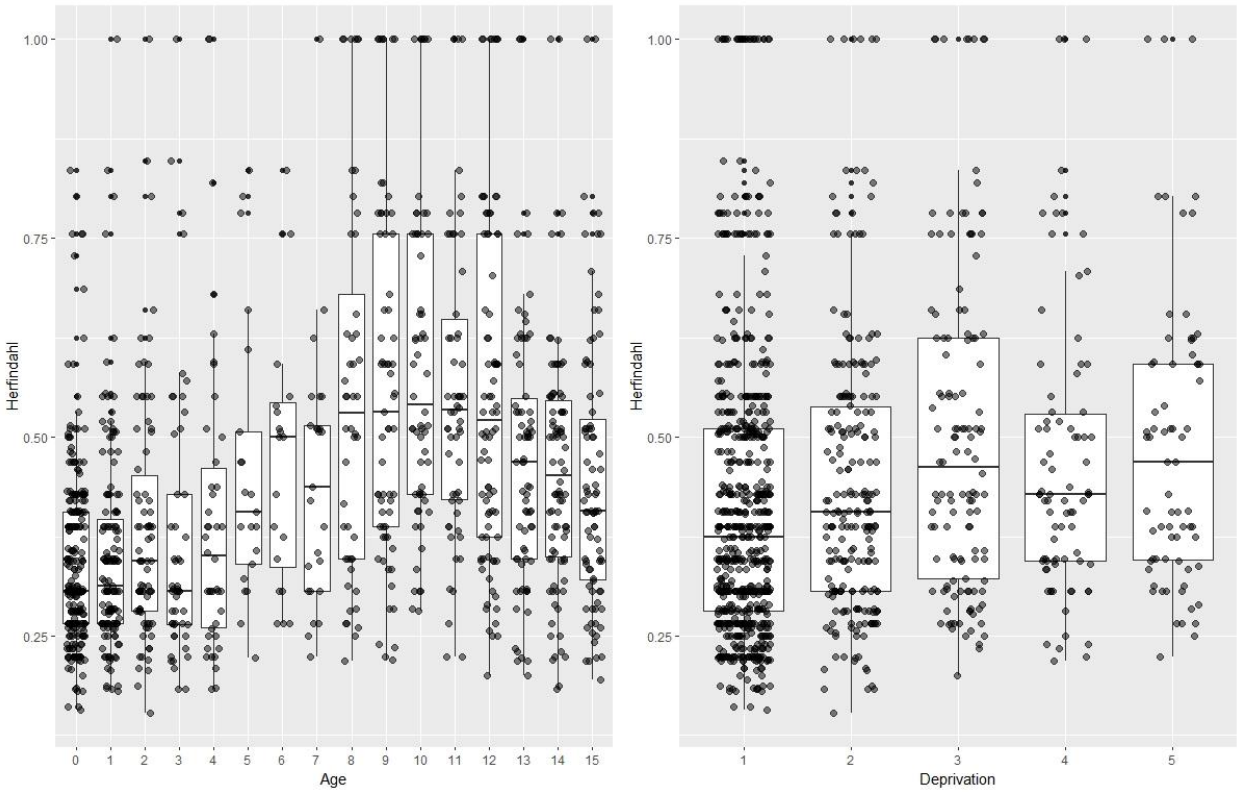


Figure 13-Heterogeneity (Herfindahl Index) of Reasons for Attendance by Age and Deprivation

Those aged 8-12 were more likely to have a greater Herfindahl index in comparison to infants under the age of one. This implied that individuals aged 8-12 generally had less heterogeneity of reasons for attendance. Those under the age of 1 had a lower Herfindahl index on average and therefore displayed greater heterogeneity of reasons for attendance over the two year period. Although there was an association between an individual's age and the heterogeneity of reasons

for attendance, the sex and IMD status of an individual was not found to be associated with their Herfindahl index (see Table 28).

Table 28-Coefficients of Linear Regression for Heterogeneity of Reasons for Attendance

	Coefficient	95% CI
Sex		
Male (REF)	0	-
Female	-0.02	(-0.04, 0)
Age		
<1 (REF)	0	-
1-4	0.02	(0, 0.05)
5-7	0.12	(0.07, 0.16)
8-12	0.22	(0.19, 0.25)
13-15	0.12	(0.09, 0.15)
Deprivation		
5 (REF)	0	0
4	0	(-0.06, 0.05)
3	0.04	(-0.01, 0.09)
2	0.01	(-0.04, 0.05)
1	-0.01	(-0.05, 0.03)
N	1194	

9.6 Discussion

9.6.1 Summary of Principal Findings

We retrospectively analysed ED attendances made by 71,143 individuals under the age of 15, over a two year period. Although a relatively small proportion of individuals were defined as high frequency attenders in their first observation year (9,700, 13.6%), over half of these individuals made at least one attendance in their second observation year (5,345, 55.1%). 1,369 individuals were defined as high frequency attenders in both observation years and were more likely to belong to the most deprived IMD category. The analysis of reasons for attendance in 1,199 individuals (making 7-13 ED attendances in the observation period) found there was less heterogeneity in the reasons for attendance in those aged 8-12 in comparison to those under the age of 1. Those aged 8-12 were more likely to make injury related attendances and less likely to make illness related attendances. Conversely, those under the age of 1 were less likely to make injury related attendances and more likely to make illness related attendances.

9.6.2 Strengths and Limitations

The availability of a multiyear ED attendance dataset (CUREd) enabled us to analyse ED use in a relatively large cohort of individuals. As this study observed an individual's attendance history for the same period of time (2 year period from an individual's first attendance), this meant all individuals had the same follow-up duration. One limitation of this study was the presence of missing values. A large proportion of reasons for attendance codes were missing for the majority of EDs in the CUREd dataset, meaning data could only be extracted from 4 EDs. Further to this, when calculating an individual's Herfindahl index some C&YP were

likely to have a large number of missing reasons for attendance and therefore data from a large proportion of individuals was also omitted.

9.6.3 Comparison with other Studies

A previous study explored heterogeneity of reasons for ED attendances in frequently attending adults aged 18 and over.[121] The study similarly found that heterogeneity increased in those with a greater number of ED attendances (see appendix, Figure 18-Mean Herfindahl and Total Attendances Made). However, when adjusting for the number of attendances an individual made, the study found that heterogeneity did not vary substantially across different age groups. This is different to findings in this study as children under the age of one had greater levels of heterogeneity in comparison to older children. As older C&YP were more likely to have a greater proportion of injury related attendances, it could be implied that older high frequency attenders were more likely to make multiple injury related attendances.

9.6.4 Implications for Practice and Further Research

This study identifies a number of high frequency attenders across both observation years, suggesting the need for further research to understand the factors contributing to persistent high frequency ED use. Qualitative studies or in-depth interviews with parents/caregivers could provide a more nuanced understanding of the drivers behind repeated ED attendance. Future research could also explore ED use over multiple years in older children to assess patterns of ED attendance as the child becomes a young adult. This could provide insights into parental/caregiver factors in high frequency ED use by C&YP. Future research could also investigate the underlying reasons for this age-related variation in the heterogeneity of reasons for attendance, providing more targeted insights for intervention. In particular,

C&YP making multiple ED attendances for similar reasons (such as injury related problems) should be screened for safeguarding issues and be signposted for support if required. This could be achieved by producing a screening tool which aims to assess C&YP who make a larger than expected number/proportion of injury related attendances in a period of time. However, the effect of age must be taken into account when considering the reasons for, and the heterogeneity of ED attendances as multiple injury-related attendances for an infant is more concerning than for a teenager for example.

9.6.5 Conclusion

The heterogeneity of reasons for attendance, in combination with the number/proportion of injury or illness attendances an individual makes can be an important marker for investigating safeguarding issues, especially in those making a large number of attendances over a number of years.

9.7 Chapter Summary

This chapter describes how C&YP attend EDs over a two year period, with a number of individuals being defined as high frequency attenders in both years. For those making a large number of attendances in their two year observation period, reasons for attendance was examined, with specific emphasis placed on understanding the heterogeneity between them. This analysis found that young frequently attending children (<1) were more likely to have a greater heterogeneity of reasons for attendance (making a variety of illness related attendances), and older children (8-12) having less heterogeneity of reasons for attendance (making a large proportion of injury related attendances).

10 Final Discussion

10.1 Chapter Outline

This final discussion chapter combines the results found in the PhD to provide research implications and recommendations. The chapter begins with an overview of the aims and primary research objectives of the PhD. A summary of the main PhD findings is then presented with the strengths and limitations of the PhD outlined. The findings of the PhD are then compared with wider research and common findings stated. The chapter then provides interpretations of the PhD findings to highlight where future research and interventions should be directed. One of the main interpretations of the PhD was the fact that the UEC system is complex with a number of interacting components. This was taken into consideration when recommendations were provided. and ends by providing an overall conclusion.

10.2 Introduction

The main aim of this PhD was to examine the use of UEC services by C&YP within the UK. Guided by background reading and input from medical professionals and health-related research experts, this aim was narrowed down to specifically focus on two areas of research. The first research area was the use of telephone triage services prior to an ED attendance by C&YP, and the second was high frequency use of EDs by C&YP. These two research areas were chosen to build a picture of an individual's UEC journey by examining the use of telephone triage services prior to attending an ED, and exploring both medical and non-medical factors associated with those who reattend. These research areas were initially examined through the implementation of two systematic literature reviews, tasked with determining what had already been published in the subject area and where the gaps in the evidence were. This helped focus the PhD analyses to fill these evidence gaps by: exploring

UEC pathways following the use of NHS 111; examining the underlying distribution of an individual's ED attendance history; recommending and implementing a novel method of analysing factors associated with high frequency use of EDs; and exploring further considerations such as the reasons for attendance and ED use over a 2 year period by C&YP.

10.3 Summary of Main Findings

10.3.1 The Use of NHS 111 and Other Telephone Triage Services Prior to Emergency Department Attendance by Children and Young People: A Systematic Literature Review

This review found that call subjects were most likely to be young children (under the age of one), suffering from illness-related symptoms such as respiratory complications and fever, or accidental injuries such as accidental ingestion and head injuries. Parental/caregiver compliance with the advice made during calls depended on the disposition provided. Parents/caregivers were less likely to comply with call advice when an ED disposition was provided in comparison to when a home care disposition was provided. One study found that non-compliance with ED dispositions was largely due to the improvement in a child's condition, parents' decision to go elsewhere and an appointment with a paediatrician. Although an older study suggested that telephone triage services could reduce the number of inappropriate visits to EDs, newer publications have suggested that telephone triage services may be leading to a number of inappropriate ED attendances by C&YP (especially when the call did not involve input from a clinical expert).

10.3.2 High Frequency Emergency Department Attendance by Children and Young People: A Systematic Literature Review

In this high frequency ED attender review, 23 publications were analysed, with the majority providing a main objective of describing and/or characterising C&YP who classified as high frequency ED attenders. Although the majority of studies used a yearly attendance threshold when defining high frequency ED attenders, this threshold ranged from 2-6 attendances (with a modal threshold of 4 across studies). Publications found that although paediatric and young high frequency ED attenders make up a relatively small number of ED attenders, they make a proportionally large number of total ED attendances. Paediatric and young high frequency ED attenders are also more likely to be younger children and have a chronic condition with a reported modal prevalence of 35.5%. A study produced in the UK found that ethnicity and deprivation was associated with high frequency attendance.

10.3.3 Use of Emergency Departments by Children and Young People Following Telephone Triage: A Large Database Study

This study of 348,401 calls to NHS 111 found that 45,746 (13.3%) led to an ED attendance within 24 hours. The time to attend ED could be categorised into two relatively distinct waves, with most attending soon after the call and a proportion attending later. Of those attending an ED after being told to do so by NHS 111, over a quarter resulted in a low acuity attendance. Young age (<1) was found to be associated with low acuity ED attendances following contact with NHS 111, irrespective of the disposition provided during calls.

10.3.4 Examining Statistical Distributions and Models for Analysis of Emergency Department Attendance Rates by Children & Young People

This study provided evidence to suggest that the number of yearly ED attendances made by C&YP likely followed a heavy tail distribution such as the discrete power law or lognormal distribution. This study proposes the use of a zero truncated or one inflated zero truncated poisson model in combination with a quantile count regression model to analyse this in C&YP.

10.3.5 Exploring Factors Associated with High frequency Emergency Department Attendance by Children & Young People: A Retrospective Cohort Study

A relatively small proportion of C&YP were defined as high frequency ED attenders (27,560, 9.6%) but were responsible for a relatively large proportion of ED attendances (105,063, 25%). High frequency attenders were more likely to be admitted to hospital after attending an ED, than occasional users. When considering factors associated with ED attendance rates in ED users, younger age groups and greater levels of deprivation were found to be associated with higher rates of attendance. This association was amplified in those attending the ED most often. Ethnicity was found to be associated with ED attendance rates, with Mixed Ethnicities and Other Ethnicities having greater rates of attendance than White individuals, and Black ethnicities having lower attendance rates in comparison to White individuals. However, with the exception of Other Ethnicities this association between ethnicity and rates of attendance diminished when considering those who attended ED the most often.

10.3.6 Examining High Frequency Emergency Department Use and Reasons for Attendance by Children & Young People: A Retrospective Cohort Study

This study retrospectively analysed ED attendances made by 71,143 individuals under the age of 15, over a two-year period. Although a relatively small proportion of individuals were defined as high frequency attenders in their first observation year (9,700, 13.6%), over half of these individuals made at least one attendance in their second observation year (5,345, 55.1%). 1,369 individuals were defined as high frequency attenders in both observation years and were more likely to belong to the most deprived categories. Those aged 8-12 were more likely to make injury related attendances and less likely to make illness related attendances. Conversely, those under the age of 1 were less likely to make injury related attendances and more likely to make illness related attendances. The analysis of reasons for attendance in 1,199 individuals (making 7-13 ED attendances in the observation period) found there was less heterogeneity in the reasons for attendance in those aged 8-12 in comparison to those under the age of 1.

10.4 Strengths and Limitations of this PhD

The biggest strength of this PhD was the availability and analysis of the CUREd research database. This database contains UEC data for one tenth of England's population, in the diverse Yorkshire and Humber region. The analysis of this data enabled large sample sizes when applying a variety of statistical methods to address the research objectives in this PhD. The existence of a common anonymised patient identification code meant NHS 111 and ED datasets could be linked. This linked dataset was explored to build a picture of UEC care pathways by C&YP.

Missing data was a major limitation of this quantitative PhD. For example when addressing the research objective exploring reasons for ED attendances in C&YP, a large proportion of

the data contained within the CUREd dataset was uncoded. As only a few EDs provided sufficient reason for attendance information, a large proportion of data was omitted in this analysis. In addition to this, for EDs using the ECDS coding system, a large proportion of codes were unusable as they often didn't follow the 6 digit coding protocol outlined by the ECDS diagnosis data dictionary. This meant the sample considered in this analysis was significantly reduced in comparison to other analyses conducted in this PhD. Missing data was a limitation in other analyses in this PhD, with ethnicity data being omitted (or not routinely collected) for NHS 111 calls.

Although the objective of this PhD was to explore UEC use by C&YP, unfortunately we had no access to linkable primary care data. This meant that although we had information regarding whether a patient was triaged by a GP prior to an ED attendance, we had no detailed information regarding those who only attended primary care services after calling NHS 111. Linkable primary care data could have improved the analysis conducted in this PhD by providing more detail regarding how C&YP use primary care services prior to UEC services. In particular, high frequency primary care use could have been assessed as a predictor of high frequency ED attendance in C&YP. In the analysis of high frequency ED attendance, it was initially hypothesised that an individual's GP practice could predict high frequency ED attendance in C&YP. However, this analysis was not possible using the data available in the CUREd dataset, as an individual's GP practice code was often split by individual GP practitioners. This meant that factors such as the distance to, and the size of individual's GP practices could not be explored in this PhD.

Although we outlined NHS 111 calls transferred to ambulance services or had an ambulance dispatched, our studies did not examine ambulance use in detail. This meant the perceived urgency of a child's healthcare need wasn't examined for parents and caregivers contacting emergency services. Analysis of emergency calls to ambulance services would be useful to

determine a child's UEC journey following assistance from emergency services. For example, this analysis could provide insights into the proportion of C&YP arriving at the ED by ambulance who then are admitted into hospital. This analysis could also explore waiting times for individuals requiring the assistance of paramedics and first responders.

A third systematic literature review was initially conducted during this PhD, and highlighted gaps in the evidence relating to high frequency ED use within household and family members. We planned (through the use of an updated version of the CUREd dataset containing an individual's unique property reference number) an analysis that links households and family members who frequently use EDs. However, delays in the availability of this data meant this analysis was not possible. This also meant that the analyses conducted during this PhD could only use data from 2014-2017 so insights into ED use both during and after the Covid-19 pandemic could not be explored. As the data is over 6 years old, the findings of this PhD may be different if repeated using up-to-date data. For example, during the Covid-19 pandemic NHS 111 was expanded to provide specific treatment and triage information for those showing symptoms of coronavirus. This means that telephone triage dispositions provided by NHS 111 during this period may be different to those outlined in this PhD. In addition to this, the proportion of C&YP provided with an ED disposition may have been lower during this period as there was a significant push by the NHS to reduce demand for hospital services, ensuring resources could be redirected to manage severe cases of coronavirus. An updated analysis exploring UEC by C&YP using current data could be used to assess the affect Covid-19 pandemic had on UEC services.

The low acuity measure used in a number of studies in this PhD was initially designed and used for adult patients. Hence a specific low acuity measure for C&YP may have been more applicable. It therefore may be more appropriate to use a low acuity measure that accounts for reasons for attendance that are low acuity for adults but not low acuity for C&YP. For

example, adult patients attending an ED with a high temperature may be defined as low acuity, but a child under the age of one attending an ED may not be low acuity due to the vulnerability of young children. The analyses conducted in this PhD project assumed individuals use paediatric EDs in the same way as other EDs. However, due to likely differences in factors such as patient profiles, wait times and admission thresholds, future research could stratify the ED type in analyses.

This PhD was quantitative in nature meaning a positivistic approach to research was adopted. However, this positivistic approach is limited to finding statistical correlations within these individuals, hence further understanding of why C&YP use UEC services may require more in-depth, qualitative techniques through closer interactions with these patients. A further limitation of the positivistic approach in relation to the healthcare data research conducted during this PhD is the assumption that data is accurate. In practice, due to human involvement in processes such as data collection and measurements, errors within this type of data can occur. This PhD provides the opportunity for future qualitative work to provide further insights into the use of UEC by C&YP.

10.5 Synthesis of Findings

To determine whether the main findings of both the systematic reviews and the research objectives converge, these PhD components were compared. This enhanced our understanding of UEC service use by C&YP.

10.5.1 Comparison of Research Objective Findings with Systematic Reviews and Wider Research

10.5.1.1 Use of Emergency Departments by Children and Young People Following Telephone Triage

The study of ED use by C&YP following telephone triage, provided similar findings to the systematic review conducted in this PhD, outlined in chapter 3. For example, both found that telephone triage calls were likely to be regarding young children (<1). When assessing parental compliance with home care call advice, the findings of both the systematic review and the study conducted in this PhD suggested that compliance was high. However, when considering compliance with ED advice provided during calls, our study found that compliance was significantly lower in comparison to the findings of the systematic review, as demonstrated by the updated forest plot below (see Figure 14).

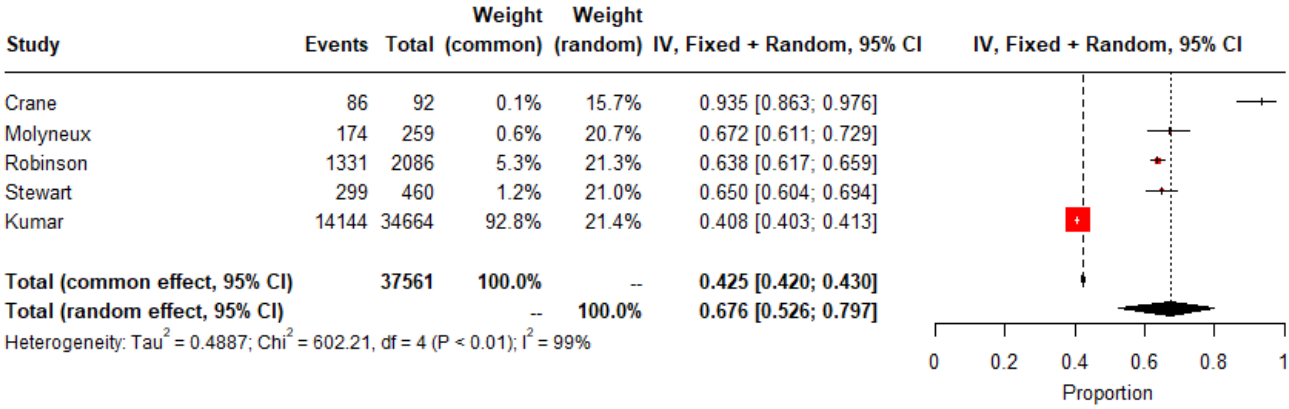


Figure 14-Updated Forest Plot to Show Compliance with ED Disposition

This is an important finding as it suggests there is less confidence in NHS 111 in comparison to other smaller telephone triage services operated within specific hospitals, or smaller

regions/districts found abroad. Our study found that a large number of calls did not involve a clinical advisor and therefore provided parents and caregivers with solely algorithm-based advice. This, in addition to the finding in the systematic review - suggesting that calls involving a clinician were less likely to lead to inappropriate ED use implies that advice provided by a clinician was more likely to be specialised for the child's need. However, caution must be taken when assessing the effectiveness of NHS 111, as the algorithm-based advice may be designed to be more risk averse to avoid dangerous situations, such as when C&YP are incorrectly advised to manage their condition at home. It may also be the case that parents and caregivers were more likely to comply with advice provided by a clinician as they had more confidence in a medical expert. Hence, future research could specifically compare parental compliance with calls both involving a clinician, and calls providing algorithm-based advice to ascertain if parents and caregivers are more likely to follow advice when provided by a clinician, irrespective of the disposition.

10.5.1.2 Examining Statistical Distributions and Models for Analysis of ED Attendance Rates in Children & Young People

Although the systematic review conducted in relation to high frequency attenders in this PhD did not highlight any studies exploring the underlying distribution of ED attendances in C&YP, other research has been conducted on this subject area in adults. Similarly to the methodological study produced in this PhD, studies found that the number of ED attendances made by adults was also likely to follow a heavy-tail distribution such as the power law distribution.[55, 155] One study extended their findings to suggest high frequency attendance in adults may describe features of complex systems due to this underlying power law distribution. A complex system in the context of UEC comprises patients, ED staff, other healthcare services and the wider social setting. As the study conducted in this PhD found a

similar underlying distribution to this publication, the complex system assumption may hold when considering C&YP. The implication of this finding is that efforts to reduce ED attendances at an individual level may not significantly impact the overall distribution, as another individual is likely to take the place of the ED user. Although this finding is conceptual, in practice it may suggest that interventions to address high frequency ED use should consider the whole UEC (and wider) system rather than just the individual.

10.5.1.3 Exploring Factors Associated with High Frequency ED Attendance in Children & Young People

As the definition of a high frequency attender differed across studies included in the systematic review, it was difficult to make direct comparisons between studies. However, the updated forest plot below suggests that our study had a greater proportion of high frequency attenders in comparison to other studies in the review (see Figure 15). In addition to this, our study also found that these high frequency attenders make a relatively large proportion of ED attendances in comparison to other studies (see Figure 16). However, these results are not surprising as we used a lower threshold of high frequency attendance in our study. To show how our data compares to the finding of the systematic review we also included these characteristics using a threshold of 4 yearly attendances in the updated forest plot. In comparison to the other large study conducted within the UK (Greenfield et al), when adjusting our high frequency attendance threshold to match their study, we found that a much smaller proportion of ED attenders were defined as high frequency attenders. However, on further inspection their study used a unique method of counting the number of attendances a high frequency attender made, spanning over a number of years. This could be the reason why the proportion figure was found to be higher in their study.

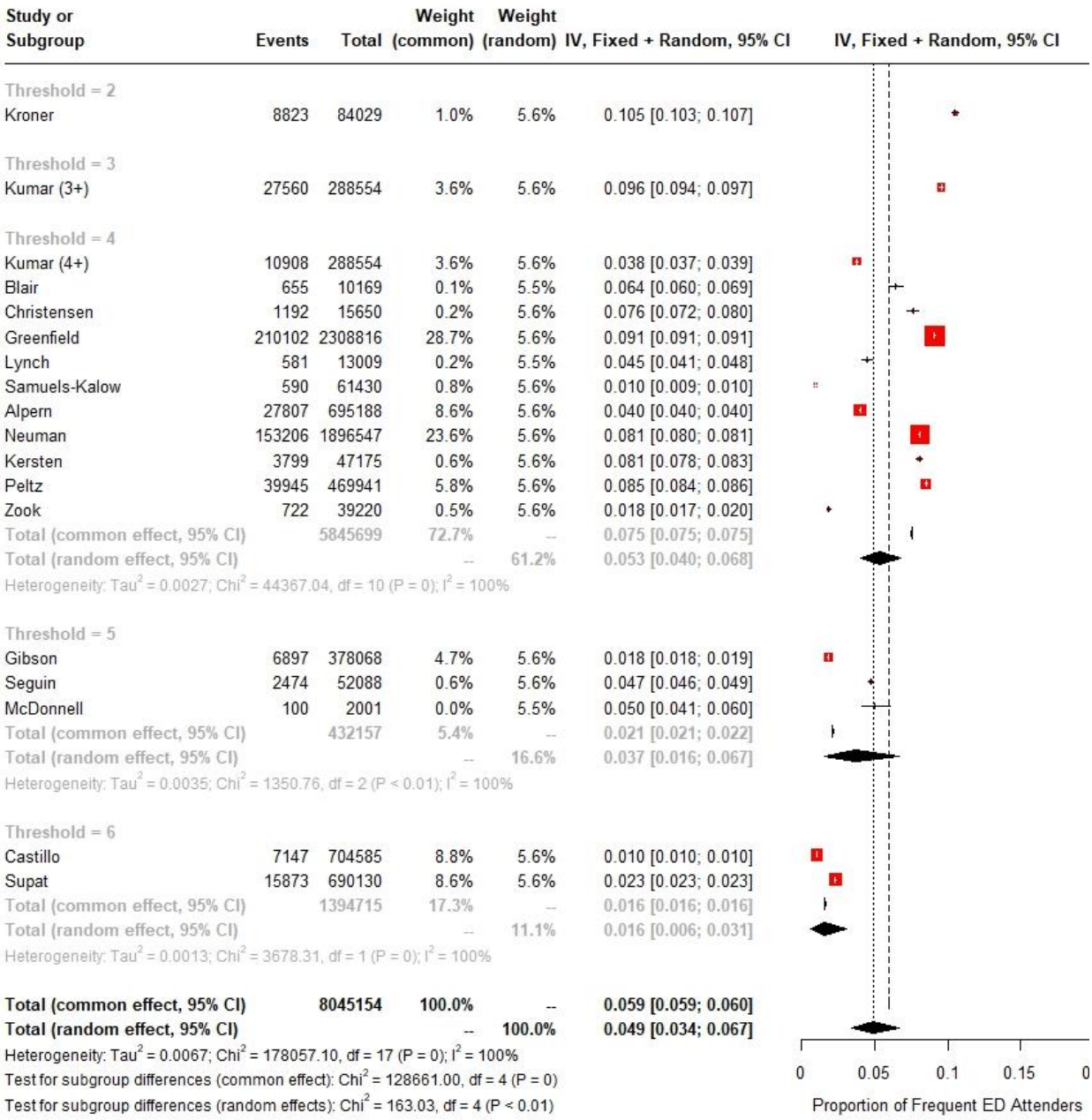


Figure 15-Updated Forest Plot to Show the Proportion of Frequent ED Attenders

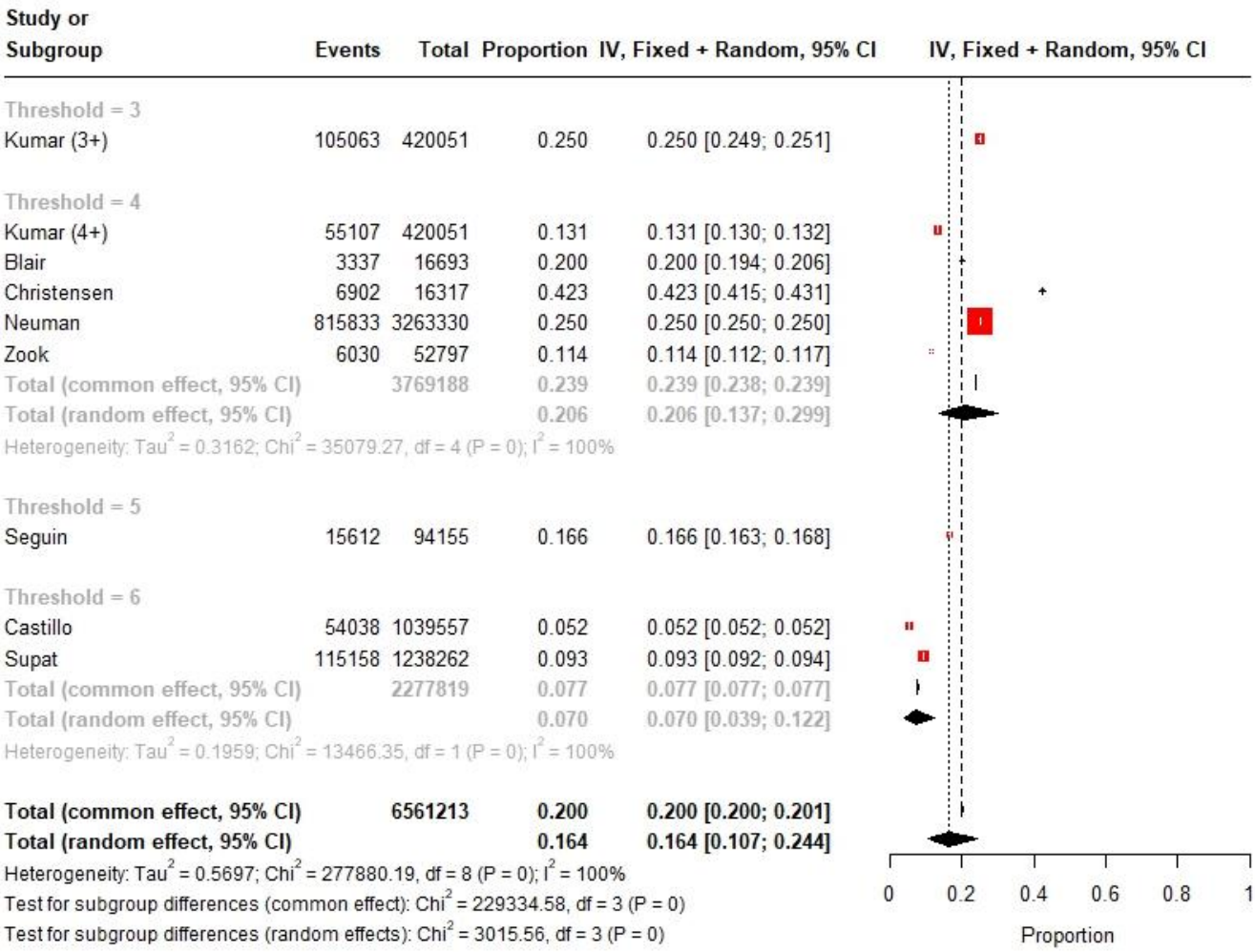


Figure 16-Updated Forest Plot to Show the Proportion of ED Attendances Frequent Attenders Make

The combination of statistical regression models used in our study had not been implemented in any other studies explored in the systematic review. However, the review did outline other studies examining similar characteristics of high frequency attendance. Age was found to be associated with high frequency ED use across all studies exploring this and was similarly found in our study. In particular, our study agreed with the general review finding that those under the age of one were found to have the greatest association with high frequency ED use. Our study additionally found that those aged 15-17 were also likely to be associated with high frequency ED use. Unlike other studies, the analysis conducted during this PhD explored factors associated with ED attendance rates specifically in those attending EDs the most (by modelling the upper tail of the ED attendance distribution using quantile regression). This provided additional information suggesting the association between the youngest and oldest C&YP and rates of attendance was amplified in those attending the most often. Although the study conducted in this PhD is the only known study to use quantile regression to analyse those attending EDs the most often, one study included in the systematic review assessed characteristics of those attending more than 20 times in a year.[83] The study concluded that all extremely high ED users had a chronic condition, with the majority being under the age of 4. When considering deprivation as a factor associated with rates of ED attendance, the majority of studies in the literature review explored this through an individual's medical insurance status. Our study explored this association directly using an index of multiple deprivation measure, and solidified the claim provided in the studies that greater levels of deprivation were associated with high rates of attendance. This was also found in the England-based study highlighted in the systematic review. Although this association is multifaceted, there is evidence to suggest that this is due to reduced access to primary care services and lower levels of health education in these areas. Additionally, the

high frequency attender systematic review also suggested that ethnicity may be associated with high frequency ED use, as both Native American children were found to be disproportionately attending EDs in the USA, and ethnic minority individuals had greater odds of being a high frequency attender in England. A Guardian analysis of NHS Digital and census data suggests that ethnic minorities in England have worse access to GPs than White individuals which may result in increased use of UEC services by these demographics.[156] However, although this association was found in our study, there was a discrepancy between the ethnic minorities more likely to have higher rates of attendance in comparison to the other UK based study. This implies that ethnic minority C&YP living in different geographical regions of the UK have different rates of attendance, even when taking deprivation into consideration. Hence factors such as systematic racism could also play a part in why those belonging to ethnic minority backgrounds are more likely to be high frequency ED users in some studies. This could also highlight sub-demographic factors such as the immigration status of ethnic minorities. The finding in chapter 9 suggesting that the most deprived ethnic minorities generally display lower rates of attendance than the least deprived ethnic minorities further highlights the heterogeneity of attendance rates across ethnic minority individuals. In particular, this finding may indicate problems in accessing UEC for migrant C&YP who use healthcare services less often for reasons such as language barriers, cultural differences and reduced understanding of the UK healthcare system. To this end, a systematic review exploring the use of health services by migrant C&YP suggests that targeted policies such as improving health literacy in combination with system changes – including cultural competence education for healthcare professionals and the improved availability of interpreters could help overcome these barriers in access to healthcare.[157]

10.5.1.4 Examining ED Use and Exploring Reasons for Attendance in Children & Young People

The systematic review of high frequency ED attenders conducted in this PhD found no studies exploring high frequency attendance over multiple years. However, one recently published study does explore this for adults.[158] The study found that a number of high frequency attenders remained high frequency attenders for 2-3 consecutive years (15,617, 14.9%). Unlike our study conducted during this PhD, the study of adult patients considered 6 years of data and also found a small number of patients remaining high frequency users for 4-6 consecutive years (3,774, 3.6%). Like other studies considering high frequency ED use, the study found that those either underinsured or uninsured were more likely to be persistent high frequency attenders with a higher prevalence of chronic conditions and comorbidities. Although we only considered two years in our study conducted in this PhD, we similarly found that a proportion of individuals were high frequency attenders over both years (1,369, 14.1%). In addition to this, we found that the reasons for attendance in those making a relatively large proportion of ED attendances in the two year period (7-13 attendances), varied across age groups. In particular we found that younger individuals (especially those under the age of 1) were more likely to attend due to a variety of illness related conditions, whereas older individuals were more likely to have greater levels of homogeneity in relation to their reasons for attendance (with a notable proportion of 8-12 year olds solely making injury related attendances).

10.5.2 Common Findings Across the Studies Conducted During the PhD

A common finding across the studies conducted in this PhD was related to the use of UEC services by young children (specifically those under the age of one). The NHS 111 study conducted in this PhD found that a large proportion of NHS 111 calls were regarding young

children. This study also found that young children were most likely to make low acuity ED attendances following NHS 111 calls, irrespective of the disposition provided. Further to this, young children were most likely to be high frequency ED users, and were found to attend with a variety of illness related complications. The reasons behind why parents and caregivers often utilise UEC services to treat their young child presents a complex interplay of medical, socioeconomic and psychological factors. Young children (<1) often have a number of minor health related problems including rashes, conjunctivitis, constipation, viruses and ear infections.[159] Although these problems are likely to rectify themselves without any further intervention, there are often signs and symptoms that indicate to parents and caregivers that medical assistance may be required. This, in part, is where the complexities begin, as factors such as the perceived urgency of their child's healthcare need (exacerbated by a young child's inability to effectively communicate their problem), and the health education of the parent or caregiver, determines the point at which they decide that medical assistance is required. In an ideal healthcare system, at this stage (in the case where there is no obvious medical emergency), the parent or caregiver would contact a paediatrician directly who would then provide medical advice. These medical experts can then determine if the child should be managed from home, require further investigation through primary care routes, or urgent care through UEC routes. Although this may be possible through private healthcare, a large proportion of parents and caregivers are unlikely to have access to paediatric specific services, and may in fact have difficulties accessing primary care services (such as GPs) in general (depending on their geographical location). Parents and caregivers may decide to contact NHS 111 to seek advice from the telephone triage service. However, as the analysis in this PhD suggests that call advice is often extremely risk averse (especially with younger children) and thus likely to advise the use of primary care or UEC services, a large proportion of these young children will be treated in UEC services.

As deprivation was found to be associated with high frequency ED use in young children, the aforementioned factors are equally important when considering parents and caregivers who frequently seek UEC for their child. Additionally, studies have found that the existence of chronic conditions and comorbidities in young children were associated with high frequency ED use. This may indicate that specific conditions such as asthma, are often poorly managed by parents and caregivers. However, EDs may have condition-specific equipment (such as paediatric nebulisers for example) which may not be easily accessed through other care pathways, meaning parents and caregivers are left no choice but to attend EDs frequently.

10.6 Interpretation of Key Findings

An important finding of this PhD was the statistical distribution underpinning the number of ED attendances C&YP make. As this was found to be heavy tailed in nature (potentially with a power law distribution), this indicates that UEC may describe features of a complex system. As complex systems have a number of moving parts this means the system's performance and behaviour cannot be understood by simply knowing one of many individual components.[160] This implies that addressing high frequency use of UEC services by C&YP in particular is not a "find and fix" problem and likely requires a holistic approach encompassing the whole healthcare system and beyond. Research has suggested that change within complex healthcare systems often use top down tools such as prescribing more regulation, restructuring and introducing stringent performance indicators.[160] However, effective change needs to factor in knowledge about the complexity of the system by producing more nuanced patient-focused interventions, thereby building momentum for change. Further to this, the World Health Organisation (WHO) suggested that a traditional approach of dealing with problems within complex healthcare systems usually involves blaming and shaming healthcare professionals.[161] Hence, the research recommendations

provided in this PhD will avoid doing this, whilst instead focusing primarily on measures to assist parents and caregivers with healthcare decision making processes.

10.7 Research Recommendations

This PhD has outlined the importance of factors such as parental decision making when C&YP use UEC services. Considerations such as the health education levels of parents/caregivers, and the perceived urgency of their child's medical need play a pivotal role when choosing the most appropriate healthcare service to treat their child. As this PhD specifically found that young children (<1) are often seen in UEC settings when other less urgent services may have been more appropriate, NHS interventions could provide further targeted healthcare support for parents and caregivers of young children. Although the NHS do currently provide these individuals with support (through regular health visits in the early stages of a child's life for example), further measures such as the provision of basic health equipment and resources for parents and caregivers of newborn babies could be widely implemented. This, in addition to a support pack containing information on how to correctly use the equipment, and user-friendly vital signs reference charts (example shown in appendix Figure 19[162]), could assist parents when choosing the most appropriate service to then access. Although this appears to be financially detrimental for the NHS, it may be the case that it reduces the cost of inappropriate UEC service use in this demographic. However, the effectiveness of the above measure does depend on the availability of other primary care services. As outlined by the association found between deprivation and higher rates of ED use in this PhD, availability of primary care services for C&YP must be addressed. Although improving the health education levels of parents and caregivers can help them determine the urgency of their child's healthcare need, factors such as parental/caregiver healthcare anxieties may still exist. This PhD suggests that parental compliance may improve when the

caller speaks to a clinician. This finding could imply that parents and caregivers often follow non-ED advice provided by medical experts as they feel reassured the health-related problem was nothing serious. A way in which this finding could affect policy and practice is by increasing the number of nurses and other medical experts involved in triage calls. However, this is constrained by capacity so other methods such as improving the medical training for call handlers may need to be implemented.

As there are currently a number of NHS, private and charitable services providing exceptional support to parents and caregivers of C&YP in the UK, it is important to note the research recommendations outlined in this section are not undermining the work they do. However, the findings of this PhD may suggest that more can be done to ensure these services are made available to parents and caregivers living in the most deprived areas. This PhD found that the heterogeneity of reasons for ED attendances in frequently attending C&YP was associated with their age. Additionally, one study explored in the high frequency attender review hypothesised that high frequency use of EDs could be used as a marker to identify children at risk for maltreatment.[93] EDs may therefore benefit from a risk assessment tool designed to assess whether C&YP should be screened for safeguarding issues. This risk assessment tool could incorporate factors such as the heterogeneity of reasons for attendance as, if a young child is making a large number of injury related attendances for example, support must be provided for the child. However, the study exploring maltreatment in children also suggested that high frequency ED use could not predict maltreatment on its own as a number of confounders exist. This implies that a screening tool may need to consider a number of factors in its design, potentially including parental/caregiver considerations such as history of alcohol or drug abuse.

10.8 Conclusion

The factors associated with the use of UEC services by C&YP represent a complex interplay of medical, socioeconomic and parental/caregiver decision making considerations. This PhD has demonstrated how large quantities of routine patient data can be used to provide insights into the use of UEC services by C&YP. However, when using routine patient data, it can be challenging to distinguish between high frequency ED users making clinically appropriate ED attendances for reasons such as chronic conditions, and those making less clinically appropriate ED attendances due to factors such as parental anxiety and reduced access to primary care services. Although targeted interventions should be implemented to assist parents and caregivers when making health-related decisions for their child, as the UEC system comprises a number of interacting components, these interventions must also consider the wider healthcare system and beyond.

Appendix

Downloaded: 20/12/2023
Approved: 19/04/2022

Akshay Kumar
Registration number: 200283357
Population Health
Programme: PhD research for school of health and related research

Dear Akshay

PROJECT TITLE: Exploring patterns of ED use by children and young people
APPLICATION: Reference Number 046123

This letter confirms that you have signed a University Research Ethics Committee-approved self-declaration to confirm that your research will involve only existing research, clinical or other data that has been robustly anonymised. You have judged it to be unlikely that this project would cause offence to those who originally provided the data, should they become aware of it.

As such, on behalf of the University Research Ethics Committee, I can confirm that your project can go ahead on the basis of this self-declaration.

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since full ethical review may be required.

Yours sincerely

Anju Keetharuth
Departmental Ethics Administrator

Figure 17-SCHARR Research Ethics Committee Approval Letter

Table 29-Supplementary Material Sensitivity Analysis (Zero-Truncated Poisson regression 2015 data)

	ED Attendance Rate	
Predictors	IRR	95% CI
Sex		
Male (REF)	1.00	1.00-1.00
Female	1.00	0.99-1.00
Age		
15-17 (REF)	1.00	1.00-1.00
10-14	0.98	0.96-1.00
5-9	0.75	0.73-0.76
1-4	1.02	1.00-1.03
<1	1.39	1.36-1.42
Deprivation		
5 (REF)	1.00	1.00-1.00
4	1.05	1.02-1.07
3	1.14	1.12-1.17
2	1.21	1.18-1.24
1	1.31	1.28-1.33
Ethnicity Group		
White (REF)	1.00	1.00-1.00
Asian	1.00	0.98-1.02
Black	0.97	0.93-1.01
Mixed	1.09	1.06-1.12
Other	1.12	1.09-1.15
N	266,704	

Table 30-Supplementary Material Sensitivity Analysis (Quantile Regression Coefficients 2015 data)

Coefficient	Estimated Coefficients & Corresponding 95% CI (Quantiles)									
	Q(0.50)	95% CI	Q(0.90)	95% CI	Q(0.97)	95% CI	Q(0.99)	95% CI	Q(0.997)	95% CI
Age										
REF=15-17	0	-	0	-	0	-	0	-	0	-
10-14	0.06	[0.0009, 0.01]	0.005	[-0.01, 0.02]	-0.02	[-0.05, 0.003]	-0.08	[-0.11, -0.04]	-0.15	[-0.22, -0.08]
5-9	-0.03	[-0.04, -0.03]	-0.11	[-0.13, -0.10]	-0.21	[-0.24, -0.19]	-0.27	[-0.31, -0.23]	-0.36	[-0.42, -0.30]
1-4	0.02	[0.02, 0.03]	0.03	[0.01, 0.04]	-0.03	[-0.06, -0.005]	-0.10	[-0.14, -0.06]	-0.22	[-0.28, -0.16]
<1	0.09	[0.08, 0.10]	0.27	[0.25, 0.29]	0.20	[0.17, 0.24]	0.12	[0.08, 0.17]	0.04	[-0.03, 0.12]
Deprivation										
5 (REF)	0	-	0	-	0	-	0	-	0	-
4	0.01	[0.004, 0.02]	0.02	[0.006, 0.03]	0.02	[-0.02, 0.05]	0.01	[-0.03, 0.04]	0.03	[-0.05, 0.11]
3	0.02	[0.02, 0.03]	0.06	[0.04, 0.07]	0.1	[0.06, 0.1]	0.09	[0.04, 0.13]	0.11	[0.04, 0.20]
2	0.03	[0.03, 0.04]	0.08	[0.07, 0.1]	0.12	[0.09, 0.16]	0.11	[0.07, 0.15]	0.13	[0.06, 0.21]
1	0.05	[0.04, 0.05]	0.14	[0.12, 0.15]	0.17	[0.14, 0.2]	0.16	[0.13, 0.20]	0.17	[0.11, 0.24]
Ethnicity Group										
White (REF)	0	-	0	-	0	-	0	-	0	-
Asian	0.001	[-0.003, 0.006]	0.01	[-0.005, 0.03]	0.005	[-0.013, 0.02]	0.007	[-0.03, 0.04]	0.007	[-0.04, 0.06]
Black	-0.01	[-0.02, 0.005]	-0.0006	[-0.04, 0.04]	-0.02	[-0.07, 0.03]	0.01	[-0.09, 0.12]	0.007	[-0.09 0.11]
Mixed	0.02	[0.007, 0.03]	0.03	[0.003, 0.06]	0.07	[0.03, 0.11]	0.07	[-0.008, 0.16]	0.15	[0.03, 0.3]
Other	0.01	[0.003, 0.02]	0.07	[0.04, 0.1]	0.1	[0.06, 0.13]	0.12	[0.06, 0.18]	0.17	[0.06, 0.28]

Table 31-Reasons for Attendance Code Mapping

Reason for Attendance	ICD-10 Codes	ICD-10 Category	ECDS Codes	ECDS Category
Injury	S codes T codes M79.9	Injury, poisoning and certain other consequences of external causes Soft tissue disorder, unspecified	01-16	Laceration Contusion/abrasion Soft tissue inflammation Head injury Dislocation/fracture/joint injury/amputation Sprain/ligament injury Muscle/tendon injury Nerve injury Vascular injury Burns and scalds Electric shock Foreign body Bites/stings Poisoning (inc overdose) Near drowning Visceral injury
Respiratory Conditions (Non-Asthma)	J codes no including J45	Diseases of the respiratory system (Excluding asthma)	25 not including 251	Respiratory conditions (Not including Asthma)
Infection/infectious disease	A codes B codes L08.9	Certain infectious and parasitic diseases Local infection of skin and subcutaneous tissue, unspecified	17	Infectious disease
Gastrointestinal Conditions	K codes R10.0	Diseases of the digestive system Abdominal and pelvic pain	26	Gastrointestinal conditions
ENT Conditions	H codes	Diseases of the eye and adnexa Diseases of the ear and mastoid process	34	ENT conditions
Central Nervous System conditions	G codes	Diseases of the nervous system	24	Central nervous system conditions (exc stroke)
Asthma	J45	Asthma	251	Asthma
Urinary Conditions	N30-N39	Symptoms and signs involving the urinary system	-	-
Vascular/Haematological Conditions	I codes not including I30-I52	Diseases of the circulatory system	21 22 23	Cerebro-vascular conditions Other vascular conditions Haematological conditions
Cardiac Conditions	I30-I52	Other forms of heart disease	20	Cardiac conditions
Mental Health	F codes	Mental and behavioural disorders	37	Social problems
Diabetes	E10-E14	Diabetes mellitus	301	Diabetes
Other conditions	R50-R69 All other codes left after above	General symptoms and signs	38 and other codes not otherwise mentioned	Diagnosis not classifiable
Missing	-	-	37	

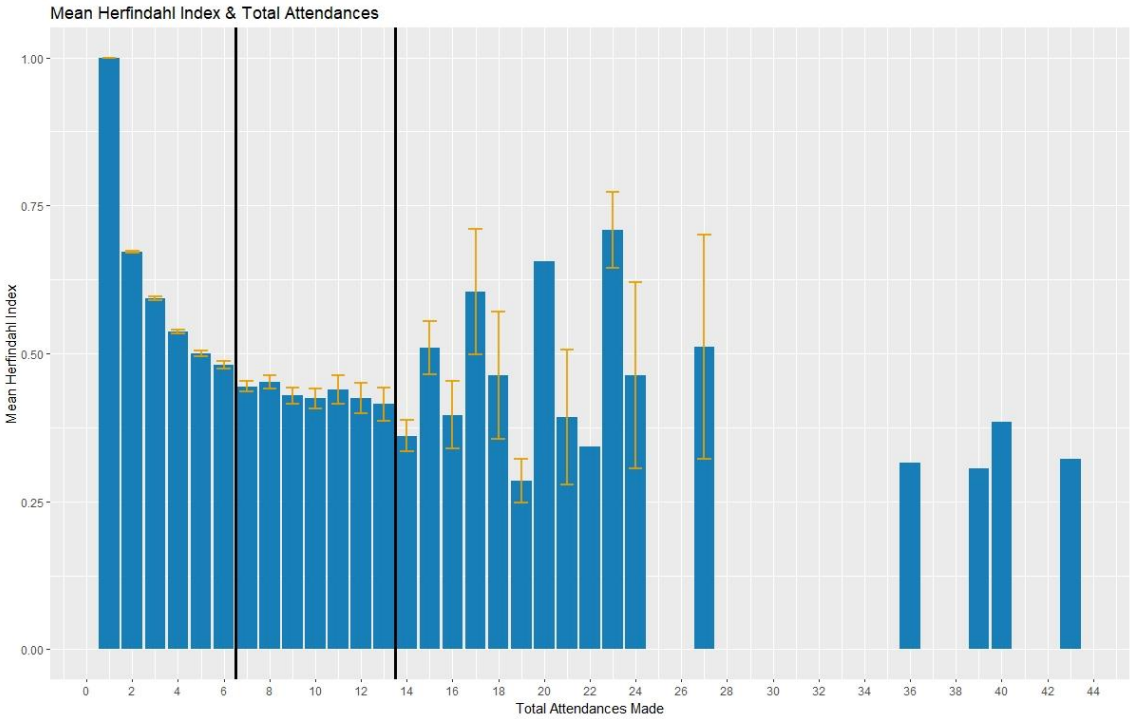
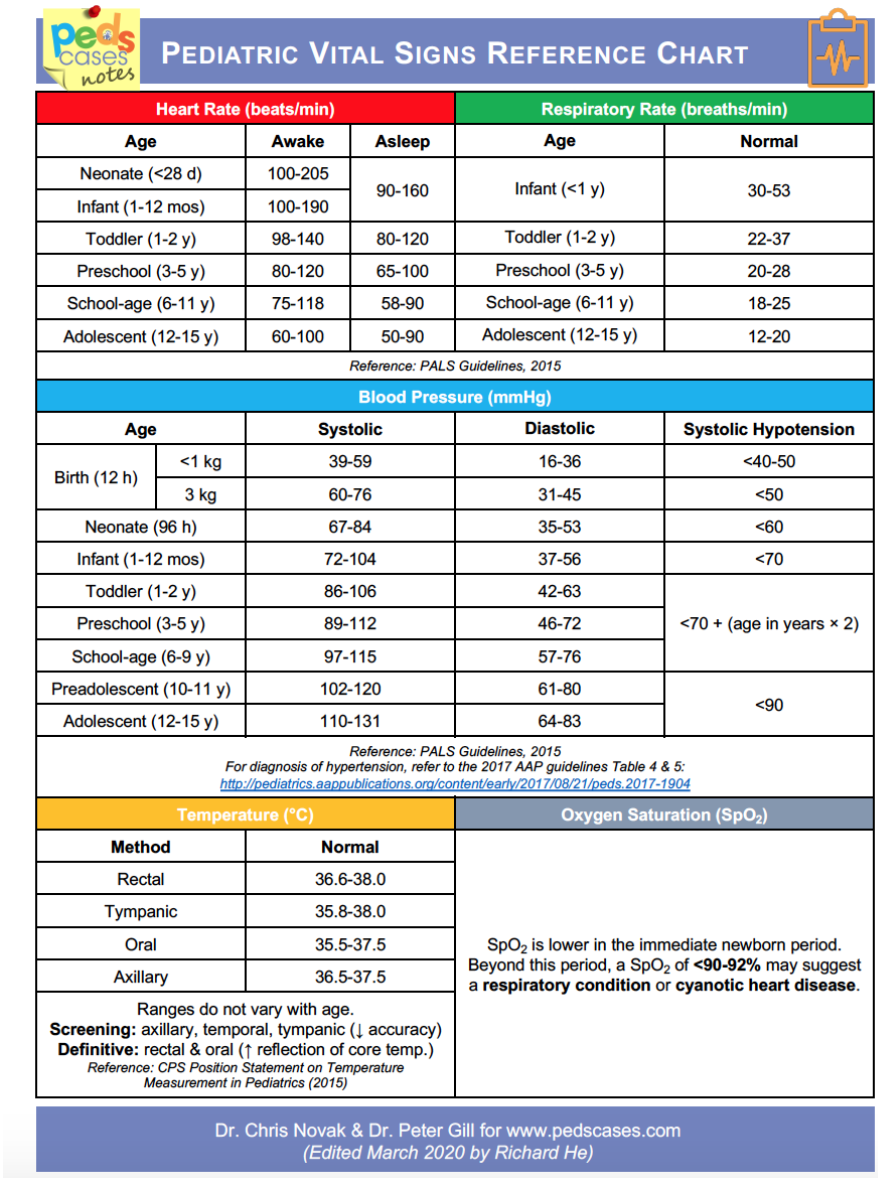


Figure 18-Mean Herfindahl and Total Attendances Made



Pediatric Vital Signs Reference Chart

Heart Rate (beats/min)		
Age	**Awake**	**Asleep**
Neonate (<28 d)	100-205	90-160
Infant (1-12 mos)	100-190	
Toddler (1-2 y)	98-140	80-120
Preschool (3-5 y)	80-120	65-100
School-age (6-11 y)	75-118	58-90
Adolescent (12-15 y)	60-100	50-90

Respiratory Rate (breaths/min)	
Age	**Normal**
Infant (<1 y)	30-53
Toddler (1-2 y)	22-37
Preschool (3-5 y)	20-28
School-age (6-11 y)	18-25
Adolescent (12-15 y)	12-20

Reference: PALS Guidelines, 2015

Blood Pressure (mmHg)

Age		Systolic	Diastolic	Systolic Hypotension
Birth (12 h)	<1 kg	39-59	16-36	<40-50
	3 kg	60-76	31-45	<50
Neonate (96 h)		67-84	35-53	<60
Infant (1-12 mos)		72-104	37-56	<70
Toddler (1-2 y)		86-106	42-63	<70 + (age in years × 2)
Preschool (3-5 y)		89-112	46-72	
School-age (6-9 y)		97-115	57-76	
Preadolescent (10-11 y)		102-120	61-80	<90
Adolescent (12-15 y)		110-131	64-83	

Reference: PALS Guidelines, 2015
For diagnosis of hypertension, refer to the 2017 AAP guidelines Table 4 & 5:
http://pediatrics.aappublications.org/content/early/2017/08/21/peds.2017-1904

Temperature (°C)

Method	Normal
Rectal	36.6-38.0
Tympanic	35.8-38.0
Oral	35.5-37.5
Axillary	36.5-37.5

Ranges do not vary with age.
Screening: axillary, temporal, tympanic (↓ accuracy)
Definitive: rectal & oral (↑ reflection of core temp.)
Reference: CPS Position Statement on Temperature Measurement in Pediatrics (2015)

Oxygen Saturation (SpO_2)

SpO_2 is lower in the immediate newborn period. Beyond this period, a SpO_2 of **<90-92%** may suggest a **respiratory condition** or **cyanotic heart disease**.

Dr. Chris Novak & Dr. Peter Gill for www.pedscases.com
(Edited March 2020 by Richard He)

Figure 19-Example of Paediatric Vital Signs Reference Chart

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