Chronic conditions in children and young people: learning from administrative data

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INTRODUCTION
Over the last century, the primary burden of disease in children and young people has shifted from infectious diseases towards chronic conditions.1 Improvements in neonatal and paediatric care for chronic conditions mean more children with previously lethal conditions are now surviving into adulthood.2,3 Depending on the definition used, 13–27% of children are affected by chronic conditions.4 Chronic conditions affect many aspects of the lives of children with consequencesthat endure into adulthood.5

Quality of healthcare for children with chronic conditions is a research and policy priority, but comes at a cost. In the USA, it is estimated that children with serious, complex chronic conditions account for 10% of admissions, but 41% of hospital charges.6 As life expectancy increases, these costs extend into adulthood. Better quality of healthcare during childhood can improve educational achievement and employment prospects and reduce disability and dependency in adulthood. To find out whether improvements in healthcare are indeed improving long-term outcomes for children with chronic conditions and their families, we need data.

In this article, we review how administrative health data can be used to evaluate the frequency of healthcare utilisation by children affected by chronic conditions and to evaluate outcomes. Administrative health data are collected routinely for non-research purposes, including for patient or service management or financial reimbursement. We focus specifically on hospital administrative databases and vital registration systems. The evidence generated by administrative hospital data on the burden and type of chronic conditions can help with planning and design of services and can be used to determine the effects of) changes in practice of policy. We also discuss how studies using administrative health databases could be extended through data linkage, to other sectors, such as education and social care, to measure outcomes in adulthood, and to data for the parents or carers, to evaluate impacts on wider aspects of children’s lives.

Evaluating chronic conditions in hospital administrative data
Evidence on healthcare utilisation is rapidly emerging as a result of the improving quality, standardisation and longevity of administrative healthcare data. In Western Australia, Canada, Scotland and the Nordic countries, administrative healthcare data have been routinely collated over decades, making it possible to evaluate patterns of healthcare for children with chronic conditions from birth to adulthood at a fraction of the cost of traditional cohort studies.7–11 Of all types of healthcare data, hospital administrative data, which primarily record hospital activity for reimbursement and commissioning purposes, are the most standardised and comprehensive across many healthcare systems and they are usually longitudinal, meaning that episodes of care for the same patient are linked over time.

Many of these databases record diagnoses in the form of International Classification of Diseases (ICD) codes. In the National Health Service (NHS), these codes are entered by professional coders based on hospital discharge records.12 We can use these codes to identify chronic conditions in hospital administrative data to measure the changing burden of chronic conditions over time, between countries and between regions or hospitals.13–15

Different classifications for chronic conditions in children have been developed in the UK and the USA (box 1), though both produce similar proportions of chronic conditions for some groups of children (figure 1). These classifications offer a starting point for studying chronic conditions in children, but more studies are needed that validate these and other classifications and how they vary.

A strength of longitudinal hospital administrative data is that children with chronic conditions can be identified in repeated attendances even though their condition might not be recorded at every admission. One limitation is that chronic conditions that rarely require hospital admission will not be captured in hospital administrative data. A second limitation is that the accuracy of hospital data depends on data quality checks, which depend on the primary purpose of the data. For instance, in England, Hospital Episode Statistics data are collected to determine hospital reimbursement. Coding of diagnoses and procedures that determine costs are well recorded (84% and 97%) for procedures and primary diagnosis compared with case notes, respectively.16 Variables not linked to reimbursement, such as ethnicity (79% complete),17 are less likely to be complete or accurate.

In the next section, we provide examples of how, despite these limitations, validated algorithms can be used to characterise chronic conditions in administrative data with sufficient accuracy for population-based analyses for service evaluation or research.18

Chronic conditions in children who die
We used hospital administrative data linked to death certification data for children who died aged 1–18 years in England, Scotland and Wales to investigate the proportion of one or more chronic conditions using the Hardelid classification (see box 1 and online supplementary appendix B).20 When analyses were based on the cause of death on the death certificate, the proportion of children who died with chronic conditions was just 57%. Looking back at all admissions over the previous year, the proportion with a chronic condition increased to 71%.21 This ‘look back’ strategy had a small effect on the proportion of children who died with cancer, but made a big difference to the proportion who died with neurodevelopmental conditions (figure 2). This approach helps to focus preventive strategies on patient groups who contribute the largest number of child deaths.

Similar studies have been conducted in the USA using the Feudtner classification (box 1),22 although without the ‘look back’ assessment of hospital admissions in the year before death.23 Using cause of death, Feudtner reported complex chronic conditions in 58% of child deaths between 1 and 18 years old in 1997, similar to the UK results based on death certification data alone (figure 1).
Ambulatory care-sensitive conditions
Among US children admitted with primary diagnoses that met the criteria for 'ambulatory care-sensitive conditions (ACSCs)', 40% had chronic conditions recorded within the past year.27 ACSCs are defined as conditions where effective community care and case management is thought to help prevent hospital admission.28 The high proportion of chronic conditions suggests that many admissions categorised as ACSC may not be appropriately managed in the community because they are medically complex.

Readmissions
Studies in both the USA and UK have investigated chronic conditions in children who are readmitted as an emergency. In both countries, hospitals are penalised financially for emergency readmissions that occur within 30 days of a previous discharge based on the rationale that emergency readmission is a sign of poor quality care at the index admission. However, research in both countries shows that many children who have an emergency readmission within 30 days (19–71%) have records in the past year indicating one or more chronic conditions.17 18 28 These findings suggest that financial penalties are reducing remuneration for readmissions for financial complexity, rather than poor quality hospital care, and may disincentivise appropriate and necessary care for children with chronic conditions.

Our analyses of readmissions in the NHS in England found that children with chronic conditions were often admitted with different primary diagnoses that related to a different organ system or symptoms rather than their chronic condition.29 Similar results have been reported for adults.30 These findings suggest that children with chronic conditions need a holistic view of their healthcare needs and may not always follow condition-specific care pathways.

FUTURE RESEARCH DIRECTIONS
We have outlined examples of cost-efficient and policy-relevant research that can be undertaken using hospital administrative data. Much more can be done. First, more studies are needed that make use of the longitudinal record to follow patients’ trajectories of healthcare, before and after diagnosis or interventions for chronic conditions to monitor quality of care and effectiveness of innovations. For example, research in England showed variation in outcomes of cardiac surgery in children as part of the Bristol enquiry into cardiac postoperative deaths.31 Hospitals
can help by systematically recording information (including dates) on the implementation of new treatments, staffing configurations or changes in practice.

Second, interventions or changes in one sector of healthcare for children with chronic conditions are likely to impact on other parts of the service. To understand these spillover effects on the service, we need more widespread linkage of data between healthcare sectors. Linked primary care and hospital data are available for research in the form of the Clinical Practice Research Datalink. However, these data currently apply to only 4% of general practice registered patients in England, and the period of linkage is restricted to the period of registration, making it hard to measure long-term outcomes for children who move practices. In addition, access to the data is very expensive and beyond the reach of many researchers.32

Linking data between hospital and other health services for children with chronic conditions is also important, particularly for children using disability services or those using child and adolescent mental health services (CAMHS). In January 2016, the Health and Social Care Information Centre (HSCIC) started data collection for a national CAMHS data set, which is expected to be available in 2017 (http://www.hscic.gov.uk/camhs). These data will be linkable to hospital administrative data; however, it will take years for longitudinal data to accrue to allow follow-up of children’s outcomes.

Third, we need linkage to parental information in order to evaluate child outcomes. Well-characterised, whole-country birth cohorts that combine maternal characteristics with longitudinal follow-up of child outcomes have been used for years in Scotland, Western Australia, Manitoba, Sweden and Denmark. Such linked data could be generated for England from the late 1990s onwards using probabilistic linkage methods to link hospital administrative data for birth episodes and by using clinical characteristics common to both mother and baby records. Such linkage would allow investigation of both mother and child trajectories of hospital care and could provide evidence about the impact of maternal chronic conditions, or pregnancy complications, on childhood outcomes. HSCIC could harness more evidence for children and families from the data it already holds by implementing probabilistic linkage methods.

Beyond healthcare: linkage to other sectors
Beyond health, schools provide important social and educational support for children with chronic conditions. Linked longitudinal administrative data within education could be used to generate

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**Figure 1** Proportion of children admitted to hospital with chronic conditions (papers used for the UK21 24-26 and USA24 27 groups: (1) children with emergency admissions for accident-related injuries; (2) children with emergency admissions for adversity-related injuries (drug/alcohol use, self-harm or violence); (3) all hospitalised children; (4) children with a first emergency admission; (5) children with a laboratory-confirmed bloodstream infection; (6) children who died; (7) children with four or more emergency admissions in 1 year. All UK papers used the ‘look-back method’ and included hospitalisations records from the 12 months prior to the index admission to define whether children had a chronic condition. US papers only included diagnosis codes entered for the index admission.

**Figure 2** Proportion of children who died aged 1–4 years with a chronic condition in England and Scotland (2001–2010) and Wales (2003–2010), according to the type of chronic condition and amount of linked data used. GU, genitourinary.
Table 1 Proportion of children affected by a chronic condition in various hospital settings

| Study       | A* | B | C | D |
|-------------|----|---|---|---|
| Age group   | %  | % | % | % |
| <1 year     | n/N| n/N| n/N| n/N|
| 1–4 years   | 67.1| 75.7| 24.4| 35.5|
| 5–9 years   | 72.9| 82.6| 29.9| 32.0*| 58.3|
| 10–14 years | 64.6| 80.3| 28.1| 35.5| 85.3|
| 15–19 years | 41.3| 72.9| 32.0*| 48.0| 32.0*| 81.1|
| Total       | 57.2| 77.1| 28.1| 31.2| 77.0| 54.3| 21.2| 16.1|
| Change youngest—oldest group | 25.8| 2.8| 7.6| 30.0| 13.2| 12.4| n/a| n/a|

*Results from study A only for children discharged home from birth and age 1 month to 1 year on admission date.
†Results from study C only for children aged 5 years rather than 5–9 years. n/a, not applicable.
‡Results from study A only up to age 18 years inclusive.
to improve service evaluation and research for public benefit.

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Data sharing statement ICD-10 codes used to define chronic conditions are available from http://bit.ly/hardeilidreport (PDF), pages 134–136. Source data can be accessed by researchers applying to the Health and Social Care Information Centre for England. Copyright 2016, reused with the permission of the Health and Social Care Information Centre. All rights reserved.

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