

# Methods for Measuring the Time of Transfer from Pediatric to Adult Care for Chronic Conditions Using Administrative Data: A Scoping Review

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**Purpose:** To describe methods used to identify the timing of transfer from pediatric to adult care within health administrative data and to identify the advantages and limitations of each method to guide future research.

**Study Design and Settings:** We conducted a scoping review to identify studies, summarized challenges of identifying the timing of transfer, and proposed methodological approaches for each.

**Results:** Studies use the following approaches to capture individuals who transfer from pediatric to adult care by 1) defining the timing of transfer by the last pediatric and first adult care visit last and 2) defining transfer to adult care based on a specific age.

**Conclusion:** There are important limitations of administrative data that must be recognized in designing studies examining the transfer to adult care.

**Keywords:** transfer to adult care, administrative data, chronic disease

## Introduction

Approximately 15% of youth have a chronic health condition that will ultimately require the transfer from pediatric to adult care.<sup>1</sup> The ultimate goal of transition care is to provide healthcare that is coordinated, uninterrupted, and developmentally-appropriate and to promote skills in decision-making and self-care.<sup>2-5</sup> However, patients with chronic health conditions and providers report inadequate support and services during the transition to adult care.<sup>6-9</sup> Emerging adulthood (18–30 years) is a particularly challenging period for people living with a chronic health condition because of the change in type and characteristics of healthcare provision, decreased parental involvement, and the developmental changes emerging adults are undergoing including; emotional, physical, financial, occupational, and social changes within a short period of time.<sup>10,11</sup> These combined challenges result in an increased risk of inadequate medical follow-up, poor self-management, emergency department visits and hospitalizations.<sup>12-15</sup>

Although the importance of transition care is well recognized, empiric data about transition outcomes remain limited. There continues to be a paucity of research on the magnitude of the problem, on factors that may mitigate the risk of complications around the transition period as well as a lack of intervention trials.<sup>16-19</sup> It is important to establish rigorous methods to identify the time of transfer to adult care in order to: 1) understand patterns of healthcare visits to pediatric and adult care providers for

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transition-age youth (eg, delays in leaving pediatric care, time gaps between final pediatric and first adult visits, and continuity of care after transfer to adult care), and 2) examine the associations of patterns of care during transition-age and important health outcomes.

Health administrative data are powerful tools in health services research to efficiently assess disease burden, healthcare utilization and outcomes in adolescents with chronic illnesses, particularly around the high-risk transition period. Specifically, using administrative data for identifying the time of transfer and for assessing outcome measures such as emergency department visits and hospitalizations may be preferable to alternatives such as self-reports, which are burdensome, may not be feasible, and may have recall bias. Further, administrative data may be useful as a supplement to patient-reported experience and outcome measures that are focused on other aspects of transition. Finally, there are benefits to understanding these issues on a population-level.

However, identifying the timing of transfer from pediatric to adult care can be difficult within health administrative data. An accurate definition for identifying this transfer is essential in reducing the risk of misclassification bias. Recognizing that health systems and administrative data sources vary between settings, it is not possible to design a single definition to identify the time of transfer that is applicable to all contexts. However, there are likely a few general approaches that could be used to measure desired variables depending on local context. Developing standardized methods would increase the quality and reproducibility of data as well as the ability to meaningfully compare results across studies. As such, our aims are to 1) describe the methods used to identify the timing of transfer to adult care within administrative health data and 2) identify the challenges with these methods as well as propose methodological approaches to overcome the challenges.

## Methods

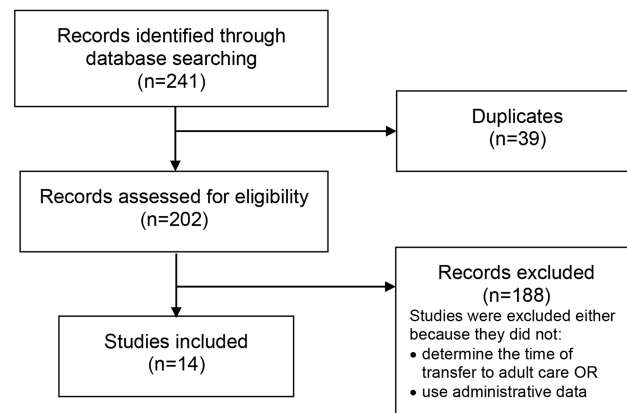
We conducted a scoping review to identify studies that used administrative data to identify the time of transfer to adult care for young adults with a chronic health condition.<sup>20</sup> We searched Embase (OVID) and Medline and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily (OVID) from the inception of the databases to August 22, 2019. The search included two broad concepts: 1) youth transferring to adult care, and 2) health administrative data. Search terms were

identified through known articles on this topic, subject experts on the team, and a librarian with expertise in database searching. The search terms included combinations of controlled vocabulary specific to the databases (ie, EmTree or MeSH) and keyword terms searched in the title, abstract or author keyword fields. The search was limited only to English language articles. Search strategies are available in [Appendix A](#). We included papers that 1) determined the time of transfer from pediatric to adult care, and 2) used administrative data; routinely collected data about health services use (eg, physician billing data and hospital and emergency department visits). All study designs were eligible and studies of any chronic condition requiring transfer to adult care were included.

Two reviewers (R.S. and M.N.) independently screened the search results, obtained the full-text of potentially eligible studies, and determined their eligibility. Discrepancies were resolved by discussion. We described each study and identified methodological approaches used by each to address specific challenges related to identification of the timing of transfer within administrative data.

## Results

Among the 241 records identified through our database search, 14 studies were included ([Figure 1](#)). [Table 1](#) describes the definitions used to identify the transfer to adult care using administrative health data. Five studies use a “transfer period” based on the date of last pediatric care visit and first adult care visit during which transfer to adult care is assumed to have occurred.<sup>21–25</sup> These visits were defined based on the specialty of the provider. Nine other studies defined the timing of transfer based on a fixed age, assuming that transfer occurred at that



**Figure 1** Flow diagram.

**Table I** Study Characteristics and Methods

First Author and Year of Publication	Location	Data Source	Disease Focus	Study Design	Methodology
Studies that define time of transfer based on last pediatric and first adult visits					
Bollegala 2017 <sup>21</sup>	Ontario, Canada	Population-based health administrative data	Inflammatory bowel disease (IBD)	Retrospective cohort	“pre-transfer”: 2 years before the last pediatric visit “transfer of care”: time between last pediatric visit and first adult visit occurring at age $\geq 18$ “post-transfer”: time from the first adult visit onward for 2 years
Hale 2017 <sup>22</sup>	England	Routine hospital administrative data	Diabetes	Retrospective cohort	“Successful transition” = any adult service contact within 6 months of last paediatric contact. “Successful retention” = first planned adult contact within 6 months of the last planned paediatric contact, and at least 2 further adult contacts within the next 2 years
Mannion 2016 <sup>23</sup>	United States	National commercial insurance administrative claims database	Juvenile idiopathic arthritis (JIA)	Retrospective cohort	The first adult visit was defined as the transfer point; this resulted in 3 distinct intervals: pediatric, transfer, and adult
Wisk 2015 <sup>24</sup>	United States	Harvard Pilgrim Health Care Claims Data	Children with chronic conditions and healthy children	Retrospective Cohort	Timing of transfer measured from 16 years to first adult-focused primary care provider visit Transfer date: date of first adult-focused primary care visit
Zhao 2018 <sup>25</sup>	Ontario, Canada	Population-based health administrative data	Inflammatory bowel disease (IBD)	Retrospective cohort	Transfer period: time between first adult gastroenterologist visit and the last pediatric gastroenterologist visit.
Studies that defined time of transfer based on age					
Blinder 2015 <sup>26</sup>	United States	5 US State Medicaid databases	Sickle cell Disease	Retrospective cohort	18th birthday was defined as the age of transfer
Cohen 2016 <sup>27</sup>	Ontario, Canada	Population-based health administrative data	Chronic health conditions	Retrospective cohort	18th birthday was defined as the age of transfer
Dickerson 2012 <sup>28</sup>	United States	Administrative data from 25 children’s hospitals within the Pediatric Health Information System (PHIS),	Sickle cell disease	Retrospective cohort	18th birthday was defined as the age of transfer
Nakhla 2009 <sup>13</sup>	Ontario, Canada	Population-based health administrative data	Diabetes	Retrospective cohort	18th birthday was defined as the age of transfer
Reilly 2017 <sup>29</sup>	Sweden	Population-based Swedish Inpatient Register	Celiac Disease	Retrospective Cohort	Pre-transition age: 16–17 years Post-transition age: 19–20 years

(Continued)

**Table 1** (Continued).

First Author and Year of Publication	Location	Data Source	Disease Focus	Study Design	Methodology
Shulman 2018 <sup>15</sup>	Ontario, Canada	Population-based health administrative data	Diabetes	Retrospective cohort	Pre-transition age: 15–17 years Transition-age: 17–19 years Early adulthood: 19–26 years (end of study)
Singh 2019 <sup>30</sup>	Wisconsin, United States	Medicaid Data	Sickle Cell Disease	Retrospective Cohort	Transition age: 19 years
Toulany 2019 <sup>31</sup>	Ontario, Canada	Population-based health administrative data	Mental illness	Retrospective cohort	Pre-transition: 12–16 years During transition: 17–18 years After transition: 19–26 years
Wijlaars 2018 <sup>32</sup>	England	Hospital Episode Statistics Admitted Patient Care data	Long-term conditions (LTCs) (defined using the International Classification of Diseases)	Cross-sectional study	Pre-transition (ages 10–15 years) and after transition (19–24 years)

age.<sup>13,15,26–32</sup> In Table 2, we summarize the challenges in identifying the timing of transfer as well as the methods that can be used to address each challenge.

### Identifying Time of Transfer Based on Pediatric and Adult Visits

Using the number and timing of pediatric and adult visits is one strategy that has been used to identify the time of transfer. To define the time of transfer studies have specified the number of visits to an adult and a pediatric provider, established a minimum time before and after the first adult visit, set a maximum time in the transfer period, and set a minimum number of visits to an adult provider.<sup>22,23,25,33</sup> To measure continuity of care after transfer, Hale et al defined successful retention as having the first adult contact within six months of the last paediatric contact and then at least two subsequent adult contacts within the next two years.<sup>22</sup> To address the challenge of identifying pediatric vs adult visits, Wisk et al used provider specialty codes from claims data to categorize providers as pediatric- or adult-focused primary care providers and then defined the time of transfer as the first adult-focused visit and the transfer gap as the time from last pediatric-focused visit to first adult-focused visit.<sup>24</sup> To ensure that transfer of care was due to age and not geographic relocation, Mannion et al set a minimum age for inclusion at the time of transfer.<sup>23</sup>

### Identifying Time of Transfer in Shared Care Models

Identifying the timing of transfer based on pediatric and adult care visits and specifically for individuals who have “shared care” defined as a pediatric visit occurring after the first adult visit presents researchers with many methodologic dilemmas on how to accurately identify transfer. Defining a transfer period is one approach used to identify the time of transfer for individuals who have a shared care model. For example, Zhao et al defined a transfer period as the time between the first adult visit and the last pediatric visit. If during this period there was shared care from both a pediatric and adult provider, the transfer period duration was assigned as the number of days from the first adult visit to the final pediatric visit.<sup>25</sup> To identify individuals who had shared care, Mannion et al required that individuals have a pediatric visit followed by an adult visit and without a subsequent pediatric visit.<sup>23</sup>

### Measuring Disease Onset, Exposures, and Outcomes Relative to the Time of Transfer

To ensure that individuals were diagnosed with a chronic condition requiring transfer to adult care, longitudinal data are needed to capture diagnoses prior to transfer to ensure

**Table 2** Approaches to Identifying the Timing of Transfer to Adult Care Within Health Administrative Data

Challenges of Identifying the Timing of Transfer to Adult Care	Methodological Approaches to Address Each Specific Challenge of Identifying the Time of Transfer
Identifying timing of transfer based on pediatric and adult visits	<ul style="list-style-type: none"> <li>Define time of transfer based on the number and timing of pediatric and adult visit.<sup>22,23,25</sup></li> <li>Measure continuity of care after the initial adult visit.<sup>22</sup></li> <li>Use provider specialty codes from claims data to categorize providers as pediatric- or adult-focused providers.<sup>24</sup></li> <li>Set a minimum age at time of transfer to ensure that the transfer was due to age and not geographic relocation.<sup>23</sup></li> </ul>
Identifying the timing of transfer for individuals who have “shared care” ie a pediatric visit occurring after the first adult visit	<ul style="list-style-type: none"> <li>Definition of a transfer period from the first adult visit to the final pediatric visit.<sup>25</sup></li> <li>Specify that individuals must have a pediatric visit followed by an adult visit and without a subsequent pediatric visit.<sup>23</sup></li> </ul>
Measuring disease onset, exposures, and outcomes relative to the timing of transfer	<ul style="list-style-type: none"> <li>Use longitudinal data to capture diagnoses prior to transfer to ensure that the condition existed prior to receipt of adult care.<sup>32</sup></li> <li>Measure outcomes after a washout period that starts after the first adult visit.<sup>25</sup></li> <li>Measure exposures and outcomes immediately before and after a specific assumed date of transfer (eg, 18th birthday)<sup>13,26-28</sup> or a period of time within which transfer is assumed to occur.<sup>15,29-31</sup></li> </ul>
Accounting for individuals who never successfully transfer to adult care	<ul style="list-style-type: none"> <li>Create a comparator group, “lost to adult follow-up” for those who never have an adult visit within the study period.<sup>21</sup></li> </ul>
<b>Other Limitations of Administrative Data</b>	<b>Methodological Approaches</b>
<ul style="list-style-type: none"> <li>Missing data:</li> <li>Physician and non-physician visits that may not be captured in administrative data sources</li> <li>Health services obtained by young adults who move away for post-secondary education</li> </ul>	<ul style="list-style-type: none"> <li>Recognize and acknowledge these potential missing data if applicable.</li> <li>If available, consider collecting from alternative data sources (eg, medical records or survey data).</li> </ul>
Risk of selection bias caused by disease severity: <ul style="list-style-type: none"> <li>Under-representation of adolescents with less severe disease who never see a pediatric provider but only ever see a family physician or an adult specialist</li> </ul>	<ul style="list-style-type: none"> <li>Adjust for unmeasured confounding factors such as disease severity by using a study design such as self-controlled case series (SCCS) design, in which patients act as their own controls.<sup>25</sup></li> </ul>
Non-comprehensive outcome data: <ul style="list-style-type: none"> <li>Administrative data do not holistically capture the transition experience (eg, patient-report experience and outcome measures and social/educational/vocational outcomes)</li> </ul>	<ul style="list-style-type: none"> <li>Link to novel data sources such as community health surveys and employment data (via tax returns), for example.</li> </ul>

that the condition existed prior to receipt of adult care. Depending on the nature of the chronic condition, this may require in-patient and/or outpatient data.<sup>32</sup> Measuring outcomes after a washout period that starts after the first adult visit ensures that events after transfer were due to the transfer and not due to clinical status during the washout period. Sensitivity analyses can be conducted to vary the length of the washout period.<sup>25</sup> Another approach is to measure exposures and outcomes immediately before and after a specific assumed date of transfer (eg, 18th birthday)<sup>13,26-28</sup> or a period

of time within which transfer is assumed to occur (eg, age 17 to 18 years).<sup>15,29-31</sup>

### Accounting for Individuals Who Never Successfully Transfer to Adult Care

If the definition of the transfer period requires an adult visit, create a comparator group, “lost to adult follow-up” for those who never have an adult visit within the study period. Outcomes can be measured during an empirically set post-transfer period after the last pediatric visit.<sup>21</sup>

## Risk of Selection Bias Caused by Disease Severity and Age at Diagnosis

Adolescents with a chronic condition who never see a pediatric provider and only ever see an adult specialist may have less severe disease or differ in their access to specialized pediatric care. This situation poses a risk of selection bias by disease severity. To mitigate this risk, Zhao et al adjusted for unmeasured confounding factors such as disease severity by using a self-controlled case series (SCCS) design, in which patients act as their own controls.<sup>25</sup> Related, if primary care in childhood is delivered by a family physician (without a pediatric specialist) there may not be a transfer to an adult provider. Further, individuals diagnosed with a chronic condition around the age of transfer who never see a pediatrician may not meet a case definition if that definition includes a visit(s) to a pediatrician.

## Discussion

In this review, we highlight several methodological issues that should be considered in the design of studies that aim to identify the timing of transfer to adult care within administrative data. We highlight several limitations of existing administrative datasets and summarize methods that have been used to address each specific challenge.

There are additional limitations to identifying the time of transfer to adult care using administrative data that were not addressed by any of the papers included in the current study. For example, defining the timing of transfer based on the last pediatric and first adult care visits is challenging if non-physician visits are not captured by administrative data. Further, pediatrician and pediatric specialist physician visits may not be reliably captured by administrative datasets if physicians do not bill fee-for-service, such as those who are paid by salary or other payment mechanisms. Adolescents may also obtain health services that are not captured by administrative data if they move away for post-secondary education and use university health services, which may underestimate healthcare use after transfer. If these missing data cannot be collected from alternative data sources (eg, medical records or survey data), they should be recognized and acknowledged. Finally, although we did not identify any studies that used transfer-specific billing codes, if available, these could be used to identify the time of transfer to adult care. In addition, the exact age of transfer within and between health systems and for

different conditions varies.<sup>32</sup> A further complicating issue is that young adults may transfer some health services at one time, while other health services are transferred at a later time. For example, university students might access a new primary care provider through school before they transfer to adult oriented speciality care. Finally, administrative data do not holistically capture the transition experience (eg, patient-report experience and outcome measures and social/educational/vocational outcomes). If available and feasible, administrative data may be linked to novel data sources that contain such information such as community health surveys and employment data (via tax returns).

Based on our findings, further empiric work is needed to compare the accuracy and feasibility of differing approaches to identifying transfer. However, because none of the reported methodologies entirely overcome the challenges of identifying the time of transfer using administrative data, there is a need for integrated pediatric and adult health information systems that span this vulnerable life stage. This is important for both clinical care and for evaluation of health service interventions for transition processes and outcomes. Measuring healthcare utilization for preventive care (office visits) may not be enough to elucidate the success of transfer. Longitudinal data to measure continuity of care in early adulthood in addition to other quality indicators and qualitative data are needed to evaluate this complex process.<sup>34</sup> Our results will inform the development of future transition care research using health administrative data.

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## Author Contributions

All authors (Rayzel Shulman, Eyal Cohen, Eric I Benchimol, and Meranda Nakhla) made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; drafting the article or revising it critically for important intellectual content; final approval of the version to be published; and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.



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## Disclosure

The authors have no conflicts of interest to declare.

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