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Inequalities in emergency care use across transition from paediatric to adult care: a retrospective cohort study of young people with chronic kidney disease in England

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J.A. conceptualised the study with supervision from S.J. and L.F. Study design was completed by J.A., with substantial contributions and revisions from S.J. and L.F. S.J. acquired the data for use in this study. J.A. completed the data analysis, interpretation of the data and drafting the work, with

supervision and guidance from S.J. throughout. All authors had substantial contributions to the revision of the work's intellectual content and approved the final manuscript.

All authors meet the following criteria:

- Cookie

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- 2. Drafting the work or revising it critically for important intellectual content; AND
- 3. Final approval of the version to be published; AND
- 4. Agreement 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

Competing Interests: The authors declare no conflict of interests related to this article.

Supplementary documents: 1 document included (title: onlineresources.pdf)

Abbreviations

- A&E Accident and Emergency
- APC Admitted Patient Care
- BIC Bayesian Information Criteria
- CKD Chronic Kidney Disease
- CYP Children and Young People
- HES Hospital Episode Statistics
- ICD International Classification of Diseases
- IMD Index of Multiple Deprivation
- IR Incidence Rate
- IRR Incidence Rate Ratio
- RE Random Effects Reeke

<u>Abstract</u>

Purpose: Transition of young people with chronic kidney disease (CKD) from paediatric to adult healthcare has been associated with poor outcomes, but few population-level studies examine trends in sub-groups. We aimed to assess sociodemographic inequalities in changes in unplanned secondary care utilisation occurring across transfer to adult care for people with CKD in England.

Methods: A cohort was constructed from routine healthcare administrative data in England of young people with childhood-diagnosed CKD who transitioned to adult care. The primary outcome was the number of emergency inpatient admissions and accident and emergency department (A&E) attendances per person year, compared before and after transfer. Injury-related and maternity-admissions were excluded. Outcomes were compared via sociodemographic data using negative binomial regression with random effects.

Results: The cohort included 4,505 individuals. Controlling for age, birth-year, age at transfer, region and socio-demographic factors, transfer was associated with a significant decrease in emergency admissions (IRR 0.75, 95% CI 0.64-0.88) and no significant change in A&E attendances (IRR 1.10, 95% CI 0.95-1.27). Female sex was associated with static admissions and increased A&E attendances with transfer, with higher admissions and A&E attendances compared to males pre-transfer. Non-white ethnicities and higher deprivation were associated with higher unplanned secondary care use.

Conclusions: Sociodemographic inequalities in emergency secondary care usage were evident in this cohort across the transition period, independent of age, with some variation between admissions and A&E use, and evidence of effect modification by transfer. Such inequalities likely have multifactorial origin, but importantly, could represent differential meetings of care needs.

Author's Summary

What is known:

- In chronic kidney disease (CKD), transfer from paediatric to adult healthcare is associated with declining health outcomes.
- Known differences in CKD outcomes by sociodemographic factors have limited prior exploration in the context of transfer.

What is new:

- Population-level data was used to examine the impacts of transfer and sociodemographic factors on unplanned secondary care utilisation in CKD.
- Healthcare utilisation trends may not reflect known CKD pathophysiology and there may be unexplored sociodemographic inequalities in the experiences of young people across transfer.

1 <u>Introduction</u>

Improvements in medical treatments have resulted in more children and young people (CYP) with
chronic kidney disease (CKD) living into adulthood. This means that transition, defined "...as the
purposeful, planned movement of adolescents and young adults with chronic physical and medical
conditions from child-centered[sic] to adult-oriented health-care systems" [1], is a key component of
their healthcare.

7 Several studies have evidenced an association between transition and poor outcomes, and evaluated

8 transition interventions [2-6]. However, most studies have smaller sample sizes, which may have

9 limited representativeness of broader childhood CKD populations and cannot delineate outcomes in

10 different sociodemographic groups [7]. Knowing if different outcomes occur by sociodemographic

11 factors may enable targeted interventions.

12 In this study, we explore how population-level data of CYP with CKD may be used to examine

13 outcomes by different sociodemographic groups across transition. Specifically, we aim to determine

14 whether there are sociodemographic inequalities in changes in unplanned secondary care use

15 associated with transfer (defined as the moment of movement to adult secondary care services) for

16 CYP with CKD, using national population data in England. Our methodology builds on previous

17 studies examining this outcome in other chronic conditions [8, 9], with the assumption that higher

18 rates of emergency care use may indicate poor disease control or other unmet care needs and are

19 indicative of higher costs and disruption to CYP's lives.

20 Materials and Methods

- 21 Study design/setting
- 22 A retrospective cohort study using routinely collected national hospital data in England, UK.

23 Data sources

24 Pseudonymised Hospital Episode Statistics (HES) records in the admitted patient care (APC, 2006/07-

25 2018/19), accident and emergency (A&E, 2007/08-2018/19) and outpatient (2006/07-2018/19)

26 datasets [9, 10].

27 Eligibility criteria

28 Participants were those in the APC or outpatient datasets who met the following criteria:

- Aged 12 to 23 years at any point in the financial years 2006/07 to 2018/2019.
- Had a diagnostic code (ICD-10 [11]) for CKD recorded < 18 years of age.
- Had outpatient records present age ≤ 16 and ≥19, and utilised both paediatric outpatient
 services (of any type) and adult outpatient nephrology, general medical or adult transplant
 services (as defined by codes used in Jarvis et. al. (2022) [9]).
- 34 Could be estimated to transfer from paediatric to adult outpatient services ≥ 12 years.
- 35 There is no consensus for ICD-10 codes for childhood CKD, so codes used were those present in lists
- 36 from both Hardelid et al. (2013) (codes of chronic childhood conditions) and Shi et al. (2021) (codes
- 37 identified based on theoretical descriptors of CKD) [12, 13]. Three additional codes were used to
- 38 identify dialysis or kidney transplant (online resource, supplementary table 1).

39 Using method previously developed by Jarvis et al. (2021), transfer was estimated by identifying the

40 age and financial year of transfer from the date of the last paediatric appointment [14]. Individuals

41 who did not have an identifiable transfer or had an estimated transfer age before 12 years were

- 42 excluded. These individuals were assumed unlikely exposed to transfer from paediatric to adult
- 43 secondary care services (and more likely indicative of acute care episodes, CYP discharged to primary
- 44 care or CYP who died or moved out of England before transition).
- 45 Determination of demographics
- 46 Sex, ethnicity, and year of birth were selected from APC and outpatient datasets based on the modal
- 47 response, unless missing. Age, index of multiple deprivation (IMD) decile, rural/urban index and
- 48 region were selected as the first recorded non-missing response for each financial year.

49 Determination of outcomes

50	The primary outcomes were a) the number of emergency hospital admissions and b) unplanned
51	attendances to A&E departments in England per person per year. Effort was made to exclude causes
52	of admissions and attendances that were likely unrelated to or that would confound the effect of
53	transfer on healthcare utilisation. These were 1) injuries caused by accidents or assaults, as these are
54	unlikely related to CKD management and may relate more to age-related risk-taking behaviour [9]; 2)
55	maternity-related admissions as these are strongly correlated with age and could confound the
56	relationship of interest (A previous study demonstrated that including these admissions created a
57	significant difference in model outputs [8]).
58	For APC data, records for individuals in the cohort were selected which were:
59	The only or first in a series of episodes (i.e., only one record per admission selected), in any
60	financial year.
61	Coded as an emergency admission.
62	Non-maternity and non-neonatal type admissions.
63	Admissions of all causes, except unintentional injuries (online resources, supplementary table
64	2).
65	For A&E data, records for individuals in the cohort were selected which were:
66	Coded as an unplanned first or follow-up attendance to an A&E department.
67	Attendances not due to assault, road-traffic accident or other unintentional injury as identified
68	by the diagnosis code (online resources, supplementary table 3).
69	For both APC and A&E datasets, duplicates were defined as any records occurring for the same
70	person on the same day and in such a case only one of these records was included. At each stage there
71	was assessment for outliers and erroneous entries: attendances per person per year more than a
72	plausible upper limit of fifty would be excluded.

For each person in each financial year, the number of eligible records in each of the APC and A&E
datasets were summed to give the number of emergency admissions or emergency department
attendances per year.

Finally, using the estimated age and year of transfer for each individual, records that were outside the
range of four years before and four years after the estimated transfer year were excluded from
analysis. A limit of four years was chosen to include sufficient data to reflect average emergency care
pre- and post-transfer, while reducing data capture on emergency care unrelated to the transfer event
[9].

81 Statistical methods

B2 Detailed descriptive statistics of cohort characteristics and the number of unplanned secondary care
B3 uses of each type per year, person and person-year were calculated.

84 Negative binomial regression with random effects (RE), with the outcome of the number of 85 emergency secondary care uses (admissions or A&E attendances respectively) per person per year, was used to calculate incidence rate ratios (IRR). Negative binomial models with RE were preferred 86 87 to Poisson regression with RE as they produced better fit of the data. Model coefficients were considered statistically significant if they met the threshold p < 0.05. Socio-demographic factors were 88 89 included in the model, alongside their interactions with transfer. Sex, ethnicity and socioeconomic 90 deprivation (Index of Multiple Deprivation (IMD), itself a composite of multiple socioeconomic 91 indicators) were included as there have been previously documented differences in paediatric or adult 92 CKD outcomes according to these factors. The rural-urban index was included based on our 93 hypothesis that the geographical structure of paediatric vs adult CKD care could impact outcomes 94 across transition. For the categories of ethnicity, IMD and rural-urban index, sub-groups recorded in 95 HES datasets were combined into logical larger sub-groups due to small numbers in some groups that 96 would limit statistical analysis. Potential confounding factors of age, birth year and age at transfer 97 were included in the model if there was a suggested relationship based on visual inspection after 98 graphing against the outcome or if they improved the fit of the model based on the Bayesian

- 99 Information Criteria (BIC) (reduced by >3 points) [15]. Region was also included in the model to
- 100 ensure differences were not accounted for by regional variations. Missing data were handled using
- 101 complete case analysis we considered this approach suitable for this study given the low level of
- 102 missing demographic data in HES datasets and the impracticality of imputation with the data
- available. All modelling was completed using Stata 17 [16].
- 104 Sensitivity analyses explored several models including alternative methods to estimate transfer (online
- 105 resource, supplementary appendix I).

106 <u>Results</u>

107 The final cohort included 4,505 individuals (Figure 1), with characteristics, including missing data,

108 described in Table 1. The source data contained many individuals who were either too young or too

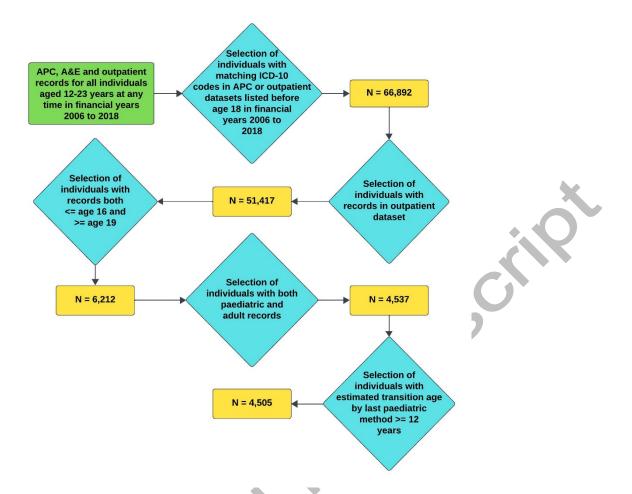
109 old to have undergone transition during the study period, as indicated by the large decrease in sample

110 size on selecting those with outpatient records at relevant ages. Mode estimated transfer age was 18

111 years (online resource, supplementary appendix D).

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- Fig. 1 Flowchart of cohort definition. Diamond boxes represent selection of records based on eligibility criteria definitions. N = number of individuals in sample. The figure shows an initial cohort selection of 66,892 individuals meeting the criteria for ICD-10 codes, decreasing to the final cohort size of 4,505 through the subsequent steps. Fig. 1 produced using Lucidchart (Lucid Software Inc., 2008).
- 119 Of 4,505 in the cohort, 3,511 individuals had emergency admission records meeting the criteria,
- equalling 10,338 emergency admissions in the four years before transfer and 8,040 in the four years
- 121 after. 3,556 individuals had A&E records meeting the criteria, equalling 11,002 unplanned A&E
- 122 attendances in the four years before transfer and 8,861 in the four years after (online resource,
- supplementary appendix G).
- 124 Mean emergency admissions per person per year before and after transfer were 0.63 (SD = 1.49) and
- 125 0.55 (SD = 1.42) respectively (range 0-35).
- 126 Mean unplanned A&E attendances per person per year before and after transfer were 0.57 (SD = 1.36)
- 127 and 0.75 (SD = 1.78) respectively (range 0-41).

- 128 Mean admissions and attendances per person-year, stratified by sex and transition status are displayed
- in figure 2. It should be noted that pre-transfer values post-19 years and post-transfer values pre-16
- 130 years are likely to be skewed by few individuals who transfer outside of this age range (see online
- 131 resources for stratification by other factors).
- 132 The incidence rate ratios (IRR) for emergency admissions and A&E attendances four years before and
- 133 four years after estimated transfer age are reported in Tables 2 and 3 respectively. For both models,
- adjustments were made for socio-demographic factors of interest as well as birth-year, age, and age at
- transfer as these demonstrated improvement in the BIC.

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- 136 To estimate any overall change in the rate of emergency secondary care usage across transition
- 137 between subgroups, adjusted IRR estimates were calculated from these models: the outputs of these
- are displayed in figure 3.
- 139 Sensitivity analyses found few significant differences in model outputs, discussed in the online
- 140 resources (appendix I).
- 141
- 142

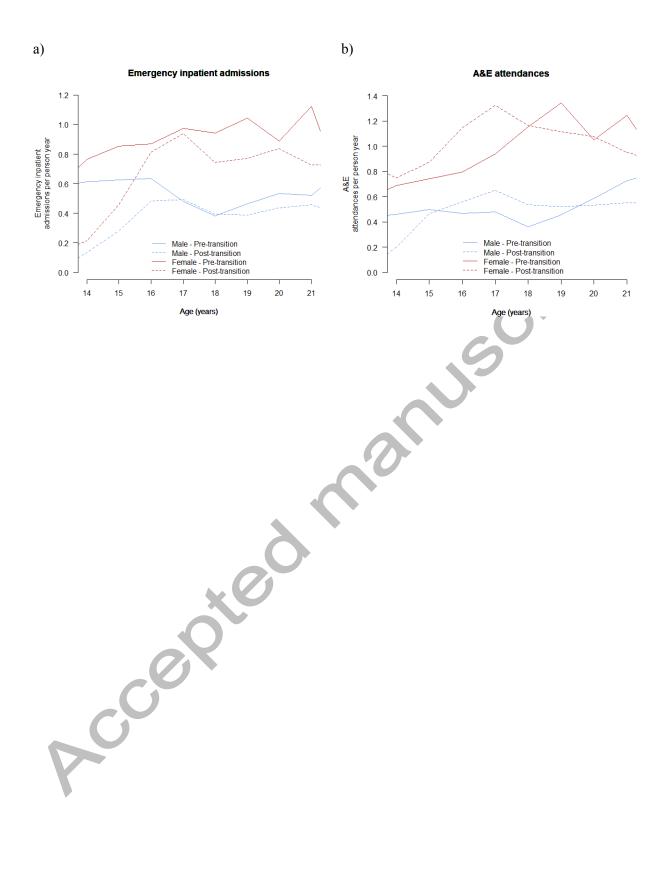


Fig. 2 a) Emergency inpatient admissions by age per person per year, stratified by transition

status and sex. Emergency inpatient admissions in this cohort are higher in females than in males
across ages 14 to 21 (around 0.7-1.0 admissions per person year in females and 0.4-0.6 in males).
In both males and females, the line of the rate of emergency admissions pre-transfer to adult care
lies pre-dominantly above the line for the rate after transfer.

148 **b)** Unplanned A&E attendances by age per person per year, stratified by transition status and sex.

149 Unplanned A&E attendances in this cohort are higher in females than in males across ages 14 to 21

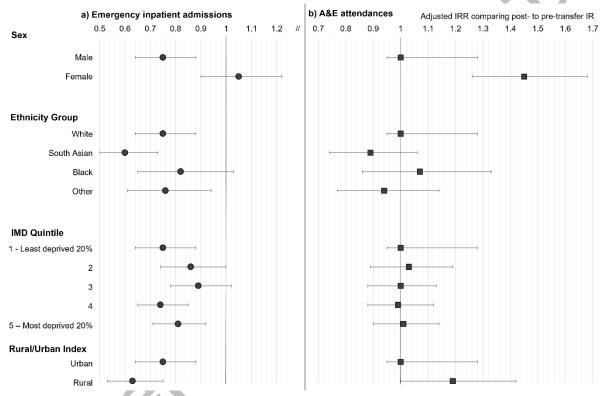
(around 1.0-1.2 per person year in females and around 0.4-0.6 in males). In females, the line of the

151 rate of A&E attendances pre-transfer lies below the line for the rate after transfer up to age 18,

where it then overlaps. In males, the pre-transfer line lies below the post-transfer between ages 15and 20.

For both figures 2a and 2b, pre-transition indicates the individual has not yet transferred to adult care, whereas post-transition indicates the individual has been transferred. Graphics for figures 2a

- 155 care, whereas post-transition indicates the156 and 2b produced using R Studio [17].
- 157



158 159 Fig. 2 Adjusted incidence rate ratios (IRR) per person-year comparing post-transfer to pre-transfer 160 values within sociodemographic groups (sex, ethnicity, Index of Multiple Deprivation (IMD) quintile 161 and rural/urban index on the y-axis) for a) emergency inpatient admissions and b) unplanned A&E 162 attendances. The circle or square represents the point estimate for each co-variate comparing the 163 difference in the incidence rate (IR) after transfer to adult care compared with before transfer to 164 adult care within that covariate group, with the whiskers representing the confidence interval for 165 this estimate. Estimates are calculated from the negative binomial regression models generated in 166 Stata 17 [16], as described in Table 2 (for figure 3a) and Table 3 for (figure 3b). Fig. 3 produced 167 using Microsoft Excel (Microsoft Corporation, 2018).

168	
169	Discussion
170	Key results
171	Controlling for socio-demographic factors and potential confounders such as age, transfer to adult
172	care was associated with a statistically significant decrease in the rate of emergency secondary care
173	admissions (IRR 0.75, 95% CI 0.64-0.88) but no significant change in the rate of attendances to A&E
174	(IRR 1.10, 95% CI 0.95-1.17) compared to pre-transfer for this population in this model. There are
175	significant differences in the overall rates of emergency care by socio-demographic factors (Tables 2
176	and 3), with female sex, South Asian and Black ethnicity groups and higher index of deprivation
177	(IMD) all associated with higher usage.
178	There is evidence of effect modification by transfer to adult care on the rates of emergency care use
179	for some sociodemographic factors: by sex, ethnicity and rural-urban index, but not IMD. However,
180	figure 3 suggests the magnitude of effect modification may not be large enough between most sub-
181	groups to result in tangible differences in the change in rate of care use across transition.
182	The biggest difference found across both models is by sex. Controlling for co-variates, female sex is
183	associated with significantly greater rates of unplanned secondary care use compared to male sex,
184	which is then further increased by transfer to adult care: whereas male sex demonstrates a decrease in
185	emergency care admissions and no change in A&E attendances with transfer, female sex is associated
186	with no change in emergency admissions and a significant increase in A&E usage.
187	Interpretation of findings
188	For CYP with CKD in this cohort, there are inequalities between different sociodemographic groups
189	in two types of emergency care use across the transition period, which may widen between males and

- 190 females following transfer to adult care and remain stable or possibly decrease for other groups.
- 191 Multiple explanations for a change in rate of emergency care use with transfer to adult care are
- 192 plausible. Decreasing emergency admissions with transfer could be due to appropriate transfer of

193 CYP with stabilised CKD or improvements in disease control with transfer. That A&E attendances do 194 not fall correspondingly suggests more attendances do not meet the threshold for admission after 195 transfer. This could be due to care needs not being met by other service provision, changes to risk-196 taking behaviour in this age group or different thresholds for admission between paediatric and adult 197 care [18] (UK paediatric inpatient services often use an 'open access' model which may bypass A&E 198 attendance for some children). Samuel et. al.'s (2014) study noted an overall increase in avoidable 199 hospitalizations of young people with end-stage kidney disease (ESKD) after transfer to adult care in the context of overall decreased hospitalizations [18]: this could indicate a trend not explored here. 200 201 Although there is limited evidence on the specific relationship between sociodemographic factors and 202 emergency care use for young people with CKD, differences in outcomes by sex, ethnic group, and 203 deprivation in this age group, mostly in studies conducted in U.S. populations, are well-documented 204 and have proposed social, structural, and biological determinants [19-22]. Male sex has been 205 previously associated with faster rates of progression in certain types of CKD, indicating alternative 206 factors may increase emergency care use among females in this cohort [23]. However, studies in 207 adults highlight poorly understood pathophysiological differences by sex in CKD which could have 208 worse impact on females and highlight that females may be underrepresented in the dialysis and 209 transplant populations [24]. A systemic review examining transition for young people with CKD 210 identified that navigation of the gap between childhood and adult services may relate to psychological, developmental, socioeconomic, and other factors [3]: these could theoretically differ 211 212 between groups examined in this study. Inequalities in this study cohort could therefore have 213 multifactorial origin, relating to differences in risk factors for emergency secondary care use, wider 214 socioeconomic determinants, or representing differential meeting of care needs. 215 We hypothesised that there could be effect modification of rural/urban status on the change in

emergency care use with transfer given paediatric nephrology outpatient services tend to be based at tertiary centres which may be less accessible compared to adult services. However, Cohen et al (2013) found that children with chronic conditions tend to move more and not necessarily to be closer to

- 219 secondary care services [25]. Thus, there may be differences in disease severity or economic
- circumstances between the rural and urban groups not detectable in this study.

221 Study Strengths & Limitations

- 222 This study utilizes whole population data, which is more representative than smaller cohorts, and
- 223 utilizes routinely collected data providing high quality on the outcome measures studied [26].
- However, the ICD-10 codes used to define the cohort have unknown specificity and sensitivity, and
- the method used to define transfer may prefer certain severities of CKD (more severe or patients with
- 226 mild CKD seen in adult general medicine departments for non-nephrology issues). Poor
- epidemiological evidence of the prevalence and distribution of childhood CKD [27, 28] limits
- assessment of the representativeness of this cohort. A cohort of children under 16 in England with
- 229 CKD stages 4 or 5 contained a higher proportion of males (64.3%), people of Asian ethnicity (23.6%),
- from the most deprived areas (30.7%) and few people in the tubulointerstitial disease category
- compared to the large proportion in this cohort [29]. These differences may be due to different
- 232 inclusion criteria, reporting of CKD categories, or invalidity of this study's selection methods.
- 233 Jarvis et al. (2021) outline how the last paediatric method used here may reduce misclassification
- compared to other methods and therefore give a more precise estimate of the impact of transfer [14].
- However, without stricter criteria regarding time between the last paediatric and first adult
- appointment, it could misclassify CYP who do not transition to secondary care as doing so. Using a
- 237 different method to estimate transfer age results in small but statistically significant differences in
- some of the model outputs (online resource, supplementary appendix I). Loss to follow-up and
- 239 discharge from care could also not be assessed, and individuals could be included in the cohort before
- 240 CKD diagnosis.
- 241 Some possible confounding or effect modulating factors aren't accounted for: CKD severity, dialysis
- use, dual renal diagnoses, and co-morbidities [30-32]. Certain causes of care use or facility types
- 243 could also skew results given they are not differentiated. Given the first component required to meet
- the study aim is to assess if there is a change in healthcare utilisation associated with transfer of care,

245 we attempted to exclude causes of care use that could be confounders for or unrelated to the effect of 246 transfer but cannot exclude all such causes. Excluding injuries and maternity-related admissions may 247 mask some transfer-related differences in utilisation of emergency care among some sub-groups 248 (particularly by sex and deprivation) and does not enable examination of total healthcare use. 249 Moreover, maternity admissions were excluded from secondary care admissions but not A&E 250 attendances (due to lack of available data in the HES A&E dataset), which could account for some of 251 the differences observed by sex and confound transfer. There is also value in exploring the links 252 between unplanned secondary care use in CKD and pregnancy, but this is outside the scope of this 253 project and may not be possible with diagnostic information provided in the HES data. 254 Without a control population, it is not possible to state if the outcomes observed in this model are 255 unique to the CKD population, although notably the relationship between transfer to adult care and 256 emergency care use does differ compared to a previous study whose population had a range of chronic 257 conditions [8]. The model may also not pick up all differences between sub-groups: despite being a 258 full population cohort, the size of ethnicity sub-groups is smaller than the estimated population sizes 259 required to find, with 80% power, a significant difference (p < 0.05) where one is present at an effect 260 size of 20%. Additionally, the retrospective nature of this study means results may not reflect current 261 standards of care in England, particularly as transition has been a service development priority for the 262 NHS [33,34]. The results of this study may not be applicable to other countries, particularly where there are different healthcare system configurations. 263

Finally, there is limited evidence for unplanned secondary care usage as a surrogate measure for
disease control and as an outcome it only partially addresses the 'triple aim' of transition care [35–
37]. There may also be reverse causality: multiple acute renal insults occurring during hospital
admissions may lead to CKD progression [21].

268

269 Study implications and directions for future research

270 Notwithstanding the above limitations, the findings in this cohort of inequalities in rates of emergency 271 care use by sociodemographic groups across transition and that transfer from paediatric to adult care 272 could be a site of effect modification for these inequalities has significant implications for future 273 research. Most studies on transfer do not focus on the differing experiences of CYP of different 274 sociodemographic groups across this challenging life period. Differences in personal factors and 275 wider social, structural, and biological determinants existing within and between sociodemographic 276 groups could impact the type of support required during transition, and thus, importantly, could enable 277 the development of targeted transition interventions designed to reduce inequalities between these 278 groups.

279 This study demonstrates how population level data could be used to explore and monitor inequalities 280 in unplanned healthcare use in CKD for different sociodemographic groups across the transition 281 period. Limitations in this study's design could be overcome by developments in future research. The 282 UK Renal Registry (UKRR) recently expanded its data collection to include children with CKD 283 stages 4 and 5 [29]. The linkage of the UKRR cohort with HES data could enable prospective cohort 284 studies examining secondary care use or CKD-specific outcomes across transition [38], using a 285 validated population of CYP with CKD and with more accurate estimates of transfer to adult care. 286 This linkage could also enable further epidemiological studies of childhood CKD through the 287 derivation of a validated list of ICD-10 codes.

288 Conclusion

289 Our study explores a novel approach to examine outcomes at the population level for young people 290 with CKD across the transition period, enabling differentiation of outcomes by sociodemographic 291 factors. Inequalities in overall rates of emergency healthcare use (excluding accident-related and 292 maternity admissions) across transition by sex, ethnicity and IMD are highlighted and there is 293 evidence for different relationships in the change in rate of emergency care use with transfer to adult 294 care for some sociodemographic sub-groups, although the magnitude of such differences are unclear. 295 Such trends in healthcare utilisation may not reflect what is known in underlying CKD 296 pathophysiology. The findings of this study should prompt further prospective, validated linkage

- studies or cluster-randomised trials in young people with CKD investigating the relationship between
- sociodemographic factors and transition; qualitative studies to understand social, psychological, and
- environmental factors which may explain any differences; and moreover, prompt those developing
- 300 transition interventions to consider how they may support those in disadvantaged groups.

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Declarations

Ethical approval: Acquisition and use of data in this manner was acquired by S.J. from the Health Research Authority (ref: 20/WA/0149) in accordance with the Declaration of Helsinki and the UK Policy Framework for Health and Social Care Research.

Consent to participate and publish: Patient consent to participate or to publication was not required for this study.

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Availability of data and materials: Access to the patient level data used in this study is governed by a Data Sharing Agreement with NHS Digital which does not permit sharing to third parties. Anyone wishing to replicate the study or perform similar analysis can request similar data from NHS Digital using the description of the data requested contained herein.

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Table 1: Descriptive statistics of the characteristics of the final cohort as defined in Figure 1. Data populations from APC and outpatient datasets. Sex and ethnic group are selected as the mode non-missing. Index of Multiple Deprivation (IMD) Quintile and Rural/Urban Index are the first recorded non-missing value for each characteristic and are derived from the recorded home postcode address. CKD Disease Group defined from the category of ICD-10 codes recorded for each individual (therefore each person may belong to more than one group if they have dual diagnoses). Further information regarding cohort descriptives in the online resources.

Demographic	Frequency in the final	Percentage of final		
~	cohort (N = 4,505)	cohort (1dp, %)		
Sex				
Male	2,228	49.5		
Female	2,241	49.7		
Missing	36	0.8		
Ethnic group				
White	3,384	75.1		
Pakistani	305	6.8		
Indian	127	2.8		
Bangladeshi	83	1.8		
Other Asian Ethnicity	105	2.3		
Mixed Ethnicities	93	2.1		
Black	201	4.5		
Other	100	2.2		
Missing	107	2.4		
IMD Quintile				
1 – Least deprived 20%	719	16.0		
2	700	15.5		
3	967	21.5		
4	924	20.5		
5 – Most deprived 20%	1,141	25.3		
Missing	54	1.2		
Rural/urban index				
Urban \geq 10K Population	3,720	82.6		
Town and Fringe	352	7.8		
Village	280	6.2		
Hamlet and Isolated Dwelling	112	2.5		
Non-English Postcode (Unknown)	5	0.1		
Missing	36	0.8		
CKD Disease Group				
Congenital anomalies of kidney and urinary	1,799	39.9		
tract (CAKUT)				
Glomerular diseases	1,363	30.3		
Tubular and tubular interstitial diseases	849	18.6		
Systemic diseases with renal involvement	717	15.9		
Unknown type	573	12.7		
Other defined cause	267	5.9		
Malignancy (renal tumours and renal	20	0.4		
involvement in systemic malignancy)				
Kidney Transplant	794	17.6		
Dialysis	2	0.04		
Dialysis		0.04		

Table 2: Adjusted Incidence Rate Ratios (IRR) of number of emergency admissions in England per person per year to secondary care from negative binomial regression model with random effects modulation of final cohort (N = 4,505). Region is also included in the model but omitted from print here. Full unadjusted and adjusted IRR values from the regression model in the online resources.

	Covariate outputs without interaction terms				Covariate outputs with interaction with transition status Reference category = Pre-transfer			
Covariate	Adjusted IRR	p-value	95% Confidence		Adjusted IRR	$\frac{\text{tegory} = P_1}{\mathbf{p} - \mathbf{value}}$	95% Confidence	
	INN		Intervals				Intervals	
Age	0.97	0.001	0.96-0.99		-	-	-	
Transition Age	1.05	< 0.001	1.02-1.08		-	-	-	
Year of Birth	0.96	< 0.001	0.94-0.97		-	-	-	
Transition		category = Pi			1			
Status		e y						
Post-transfer	0.75	< 0.001	0.64-0.88		-	-	-	
Sex	Reference	category = M	lale	•				
Female	1.40	< 0.001	1.29-1.49		1.40	< 0.001	1.29-1.53	
Ethnicity	Reference	category = W	hite					
South Asian	1.30	< 0.001	1.16-1.46		0.80	0.001	0.71-0.91	
Black	1.38	< 0.001	1.16-1.65		1.09	0.33	0.91-1.30	
Other	1.12	0.13	0.97-1.31		1.01	0.91	0.86-1.19	
Index ofReference category = 1 – Least deprived								
Multiple								
Deprivation								
Quintile						-		
2	0.98	0.72	0.86-1.11		1.14	0.11	0.97-1.35	
3	1.10	0.13	0.97-1.24		1.19	0.03	1.02-1.38	
4	1.24	< 0.001	1.11-1.40		0.99	0.91	0.85-1.15	
5 – Most	1.15	0.02	1.02-1.29		1.08	0.31	0.93-1.25	
deprived								
Rural/urban	Reference	category = U	rban (>=10K P	opi	ulation)			
index								
Rural (Town,	1.08	0.16	0.97-1.19		0.84	0.008	0.74-0.96	
Fringe, Village								
or Other)								
PC								

Table 3: Adjusted Incidence Rate Ratios (IRR) of number of unplanned accident and emergency attendances (A&E) in England per person per year from negative binomial regression model with random effects modulation of final cohort (N = 4,505). Region is also included in the model but omitted from print here. Full unadjusted and adjusted IRR values from the regression model in the online resources.

	Covariate outputs without interaction terms				Covariate outputs with interaction with transition status Reference category = Pre-transfer			
~ •								
Covariate	Adjusted	p-value	95%		Adjusted	p-value	95%	
	IRR		Confidence		IRR		Confidence	
•	1.02	0.01	Intervals				Intervals	
Age	1.02	0.01	1.00-1.04		-	-	-	
Transfer Age	1.00	0.77	0.98-1.03		-	-	-	
Year of Birth	1.01	0.14	1.00-1.02		-	-		
Transition Status	Reference of	category $= P_1$	re-transfer					
Post-transfer	1.10	0.18	0.95-1.27		-		-	
Sex	Reference of	category = N	lale					
Female	1.45	< 0.001	1.34-1.56		1.31	< 0.001	1.22-1.42	
Ethnicity	Reference of	category = W	/hite				•	
South Asian	1.13	0.05	1.00-1.27		0.80	< 0.001	0.71-0.90	
Black	1.11	0.24	0.93-1.33		0.96	0.71	0.82-1.14	
Other	1.15	0.07	0.99-1.34	Ň	0.85	0.03	0.74-0.98	
Index of Multiple	Reference category = 1 – Least deprived							
Deprivation								
Quintile								
2	1.16	0.03	1.02-1.32		0.93	0.38	0.80-1.09	
3	1.29	< 0.001	1.15-1.47		0.90	0.17	0.78-1.04	
4	1.25	< 0.001	1.11-1.42		0.90	0.14	0.78-1.04	
5 – Most deprived	1.30	< 0.001	1.15-1.46		0.92	0.22	0.80-1.05	
Rural/urban	Reference category = Urban (>=10K Population)							
index							1	
Rural (Town,	0.79	<0.001	0.70-0.88		1.08	0.23	0.95-1.23	
Fringe, Village or								
Other)								

Figure Legends

Fig. 3 Flowchart of cohort definition. Diamond boxes represent selection of records based on eligibility criteria definitions. N = number of individuals in sample. The figure shows an initial cohort selection of 66,892 individuals meeting the criteria for ICD-10 codes, decreasing to the final cohort size of 4,505 through the subsequent steps. Fig. 1 produced using Lucidchart (Lucid Software Inc., 2008).

Fig. 2 a) Emergency inpatient admissions by age per person per year, stratified by transition status and sex. Emergency inpatient admissions in this cohort are higher in females than in males across ages 14 to 21 (around 0.7-1.0 admissions per person year in females and 0.4-0.6 in males). In both males and females, the line of the rate of emergency admissions pre-transfer to adult care lies pre-dominantly above the line for the rate after transfer.

b) Unplanned A&E attendances by age per person per year, stratified by transition status and sex. Unplanned A&E attendances in this cohort are higher in females than in males across ages 14 to 21 (around 1.0-1.2 per person year in females and around 0.4-0.6 in males). In females, the line of the rate of A&E attendances pre-transfer lies below the line for the rate after transfer up to age 18, where it then overlaps. In males, the pre-transfer line lies below the post-transfer between ages 15 and 20. For both figures 2a and 2b, pre-transition indicates the individual has not yet transferred to adult care, whereas post-transition indicates the individual has been transferred. Graphics for figures 2a and 2b produced using **R** Studio [17].

Fig. 4 Adjusted incidence rate ratios (IRR) per person-year comparing post-transfer to pre-transfer values within sociodemographic groups (sex, ethnicity, Index of Multiple Deprivation (IMD) quintile and rural/urban index on the y-axis) for a) emergency inpatient admissions and b) unplanned A&E attendances. The circle or square represents the point estimate for each co-variate comparing the difference in the incidence rate (IR) after transfer to adult care compared with before transfer to adult

care within that covariate group, with the whiskers representing the confidence interval for this estimate. Estimates are calculated from the negative binomial regression models generated in Stata 17 [16], as described in Table 2 (for figure 3a) and Table 3 for (figure 3b). Fig. 3 produced using Microsoft Excel (Microsoft Corporation, 2018).

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