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Ethnic differences and inequities in paediatric healthcare utilisation in the UK: a scoping review

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ABSTRACT

Background Despite the increased policy attention on ethnic health inequities since the COVID-19 pandemic, research on ethnicity and healthcare utilisation in children has largely been overlooked.

Objectives This scoping review aimed to describe and appraise the quantitative evidence on ethnic differences (unequal) and inequities (unequal, unfair and disproportionate to healthcare needs) in paediatric healthcare utilisation in the UK 2001–2021.

Methods We searched Embase, Medline and grey literature sources and mapped the number of studies that found differences and inequities by ethnic group and healthcare utilisation outcome. We summarised the distribution of studies across various methodological parameters.

Results The majority of the 61 included studies (n=54, 89%) identified ethnic differences or inequities in paediatric healthcare utilisation, though inequities were examined in fewer than half of studies (n=27, 44%). These studies mostly focused on primary and preventive care, and depending on whether ethnicity data were aggregated or disaggregated, findings were sometimes conflicting. Emergency and outpatient care were understudied, as were health conditions besides mental health and infectious disease. Studies used a range of ethnicity classification systems and lacked the use of theoretical frameworks. Children's ethnicity was often the explanatory factor of interest while parent/caregiver ethnicity was largely overlooked.

Discussion While the current evidence base can assist policy makers to identify inequities in paediatric healthcare utilisation among certain ethnic groups, we outline recommendations to improve the validity, generalisability and comparability of research to better understand and thereby act on ethnic inequities in paediatric healthcare.

BACKGROUND

Ethnic diversity in the UK has grown considerably in the last few decades, with the proportion of some minority ethnic groups doubling between the 2001 and 2011 census. At the time of the 2011 census, nearly 11 million people in England and Wales identified as belonging to an ethnic group other than White British.^{1–3} While differences in health outcomes between ethnic groups have been observed in the UK for some time, understanding and addressing ethnic inequities in health and healthcare became an enhanced policy imperative more recently following the starkly

disproportionate impact of COVID-19 on minority ethnic communities.⁴

However, in trying to understand the complex relationship between ethnicity and health, the majority of research has focused on health outcomes rather than healthcare access and utilisation.^{5 6} Research concerning healthcare utilisation has centred on adults or the general population, with children largely overlooked. A recent rapid review commissioned by the National Health Service (NHS) Race and Health Observatory found that quantitative data on maternal and neonatal healthcare use in the UK are inconsistent and studies on neonates are particularly scarce.⁶

It is also unclear whether the evidence on ethnic inequities in paediatric healthcare utilisation in the UK is sufficient for policy making, commissioning and service planning, particularly whether findings about ethnic variation in healthcare use can be interpreted as inequitable. Throughout this paper, we use 'ethnic variation' as an umbrella term to capture both ethnic differences (unequal healthcare use) and ethnic inequities (unequal and unfair or disproportionate to health needs and health outcomes). This delineation is important from a policy perspective. While action is needed to address ethnic differences in healthcare utilisation that stem from differences in disease burden, these are distinct from actions to address inequities in healthcare utilisation that persist even after accounting for healthcare need.⁷

We conducted a scoping review to identify and appraise the current evidence, focusing on studies that quantified differences between ethnic groups or between observed and expected proportions of children who used healthcare within an ethnic group. We aimed to describe the quantity and quality of the evidence base, identify research gaps and develop recommendations for future research. We also aimed to summarise which studies reported ethnic variations in paediatric healthcare utilisation, for which ethnic groups and outcomes and whether they attempted to distinguish between ethnic differences and inequities.

METHODS

This review was conducted in line with the scoping review framework developed by Arksey and O'Malley⁸ and enhanced by Levac and colleagues,⁹ and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist¹⁰ (online supplemental appendix 1).



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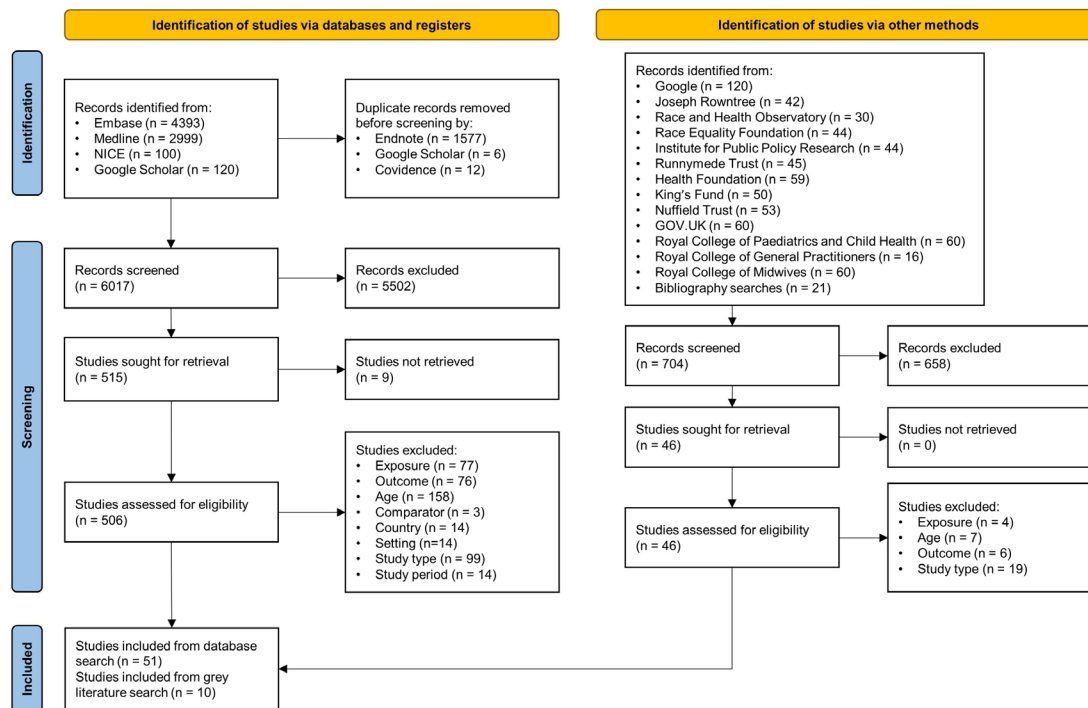


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. NICE, National Institute for Health and Care Excellence.

We define ethnicity as a social construct, self-identified and influenced by characteristics such as one's cultural identity, nationality, language, heritage, migration history and religion, as well as the evolving cultural, political and social dynamics within societies.¹¹ For healthcare utilisation, we adopted the definition of 'realised access'¹² to health and medical services provided by the NHS, which was quantitatively measured through direct contacts with these services.

Information sources

Empirical studies were sourced from Embase and Medline via Ovid. Grey literature was sourced from Google, Google Scholar, National Institute for Health and Care Excellence (NICE) and the websites of organisations known to publish on ethnicity, inequalities and health (figure 1).

Search strategies

We developed search strategies with the assistance of a librarian. Database search strategies included text word terms and subject heading terms for a combination of the following concepts: ethnicity AND paediatric AND healthcare utilisation AND UK. Database searches were filtered by year (2001–2021) and by country using validated filters developed by NICE.¹³ An example of a full database search strategy and additional information on grey literature searches are presented in online supplemental appendix 2.

Outcomes

Primary outcomes included attendance at face-to-face or remote healthcare appointments at any level of the healthcare system, uptake of preventive care, hospital admissions and emergency department attendances. Secondary outcomes included additional characteristics of healthcare use, such as referrals, failure to attend appointments, length of stay, readmissions, escalation to high dependency and intensive care, discharge, timing of

healthcare (eg, wait times or delays) and costs incurred by the healthcare system.

Study selection

Two reviewers conducted title, abstract and full-text screening (CXZ all studies; TB and CO half each). The rest of the authorship team assisted to resolve conflicts. Full inclusion and exclusion criteria are presented in online supplemental appendix 3. We included primary research or evaluation conducted in the UK that contained data from 2001 onwards and quantified differences between ethnic groups or between observed and expected proportions of individuals who used healthcare within an ethnic group. Since transition from paediatric to adult health services in the UK is not based on a single age cut-off,¹⁴ the paediatric population was defined as children and young people in the context of the type of service under investigation.

We included studies that used child and/or parent/caregiver ethnicity as a primary explanatory factor or as part of a group of multiple explanatory factors. We excluded studies that only used ethnicity as a confounder in statistical modelling because these studies often did not present results by ethnicity, thus limiting extraction and the ability to address our study's objectives. We excluded studies that used healthcare utilisation metrics as a proxy measure for other outcomes (eg, hospitalisations as a measure of disease prevalence), or described intended or anticipated uptake of service. Studies concerning healthcare experiences, attitudes, access barriers and facilitators were also outside of the scope of this review.

Charting (extraction) and appraisal

We developed a data charting form¹⁵ which two reviewers (CC and TB) piloted on five studies and iteratively refined with the authorship team.⁹ Data items were extracted by one reviewer (CXZ) and included: citation details, study period, location, participant characteristics, ethnicity, aims, methodology, outcome

measures and key findings (online supplemental appendix 4). One reviewer (CXZ) appraised studies using the NICE quality appraisal checklist for quantitative studies reporting correlations and associations.¹⁶ Only aspects of studies relevant to ethnicity and outcomes of interest were extracted and appraised.

Collating and summarising (synthesis)

The number and proportion of studies were described by: year, location, age, ethnicity, healthcare utilisation outcome, health topic, study methods, whether the study found ethnic variations and whether they attempted to distinguish ethnic differences from inequities through their methodology (eg, adjusting for healthcare need) or by choosing outcomes that are assumed to be a normative need for all children (eg, vaccination) or no children (eg, non-attendance, avoidable care).

Patient and public involvement

We held an online consultation workshop with a patient and public involvement (PPI) advisory group to triangulate the findings with parents' perspectives and develop recommendations for future research.⁹ The PPI group consisted of five mothers from different ethnic backgrounds across England, recruited as part of a wider research project.

RESULTS

Of the 8316 studies identified in database and grey literature searches, 61 were included for extraction and synthesis (figure 1).

Year, location and age of the child

Individual study details are summarised in online supplemental appendix 5. Studies were published between 2004 and 2021 and increased in number over the years. Years in which studies were conducted were distributed relatively evenly between 2001 and 2015, with a decrease in the latter half of the 2010s, likely an artefact of a lag in data availability (online supplemental appendix 6). Only five (8%) reported findings by ethnicity over time (ie, stratified by year). Studies were largely concentrated in England (41, 67%), with 23 (56%) of English studies conducted in a specific region or city, including 13 (32%) in London. Eight (13%) were UK-wide studies (online supplemental appendix 6). Nearly a third of all studies (18, 30%) presented age-specific results (ie, stratified by age).

Ethnicity

For most studies, ethnicity of the child was the factor of interest (49, 80%), with seven (11%) studying the ethnicity of the parent/caregiver, five (8%) not specifying which and none studying both. Ethnicity was more often included in a group of multiple explanatory factors under investigation (37, 61%) as opposed to being the primary factor of interest (24, 39%). The classification of ethnicity varied widely between studies, with the majority using custom groupings (42, 69%). Ten (16%) made a binary comparison of all minority ethnic groups and White or White British groups. Nine studies (15%) used Office for National Statistics (ONS) England and Wales census 2001 or 2011 aggregated five-level groupings, and only three (5%) used the 2001 census disaggregated 16-level groupings (online supplemental appendix 7). The most frequently used comparator ethnic group was White (28, 46%).

Outcomes in the included studies

Utilisation of primary and preventive care and hospitalisation were most frequently studied (22, 36% each), followed closely

by secondary outcomes like step-up to intensive care and length of stay (21, 34%). Outpatient and community care (9, 15%) and emergency department attendance (7, 11%) were least studied. Vaccination studies comprised over half (13, 59%) of primary and preventive care studies.

Methodology used in the included studies

The majority of studies assigned ethnicity using routine administrative health data (48, 79%), while the remainder elicited self-reported or parent-reported ethnicity via surveys, interviews and focus groups. Most presented descriptive quantitative findings such as summary statistics and proportions (53, 87%). Just over half proceeded to examine unadjusted statistical associations (35, 57%) with fewer presenting adjusted associations (27, 44%). Reporting of participant characteristics also varied widely, with child age (43, 70%), sex or gender (36, 59%), clinical conditions or comorbidities (28, 46%) and aggregated area-level socio-economic status (26, 43%) being the most frequently reported. Other factors relevant to the study of child health and ethnicity such as pregnancy and birth outcomes, migration status, religion and languages spoken were rarely reported.

Ethnic differences and inequities

The majority of studies (54, 89%) found ethnic variation in healthcare utilisation for at least one ethnic group. Fewer than half (27, 44%) of all studies attempted to distinguish between differences and inequities. Nine (15%) attempted to identify inequities through methodological design (such as adjusting for measures of healthcare need), and the rest (18, 30%) did so because the outcomes chosen were assumed to be a normative need for all children (eg, vaccination) or no children (eg, non-attendance, avoidable care). Figure 2 shows that less than half of the studies that reported ethnic variation had attempted to look for inequities, while nearly all the studies that found no ethnic variation had tried to address this issue. Figure 3 focuses only on the studies that found ethnic variation, showing the number of studies by ethnic group, outcome and whether the finding was a difference or inequity. In primary and preventive care, inequities in utilisation were reported across all census ethnic groups, but most frequently in children of Mixed/Multiple and White ethnicities when ethnicity was aggregated,^{17–21} and African, Caribbean, Pakistani, Bangladeshi and White Irish ethnicities when disaggregated.^{18–20 22–26}

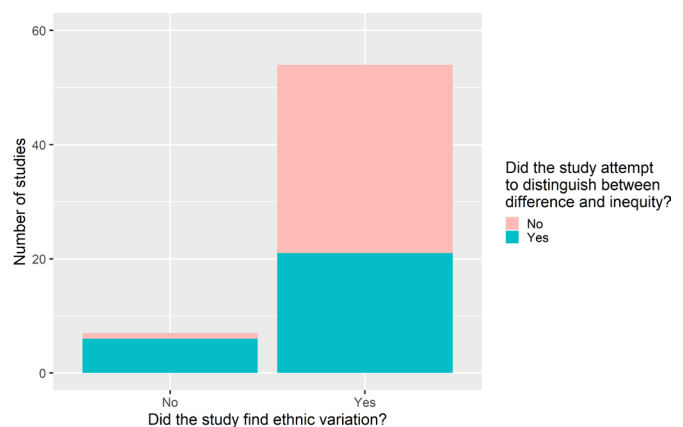


Figure 2 Number of studies by whether the study found any ethnic variation, stratified by whether the study attempted to distinguish between difference and inequity.



Figure 3 Number of studies that found ethnic variation, stratified by ethnic group, healthcare utilisation outcome and whether the study examined ethnic differences or inequities. 3A shows studies that used aggregated ethnic groups. 3B shows studies that used disaggregated ethnic groups.

Quality of evidence

Quality ratings for individual studies are presented in online supplemental appendix 8. All had low (35, 57%) or medium (26, 43%) internal validity. The majority also had low (14, 23%) or medium (40, 66%) external validity, though some were high (7, 11%). For cohort studies, none compared follow-up time between ethnic groups to assess bias. Custom aggregations of ethnic groups were often made to achieve analytical power, which limited comparability between studies. Forty-one studies (67%) did not provide any theoretical justification for their analytical methods including variable selection and 16 (26%) provided minimal justification. Only four (7%) provided a moderate amount of information and none provided a theoretical framework.

Results for Mixed/Multiple ethnic groups were presented in studies' tables and figures but received less mention in the body of text than Black and Asian ethnic groups, or were combined with Other ethnic groups and therefore not able to be interpreted meaningfully. It was sometimes unclear why higher or lower utilisation was interpreted as inappropriate for the health service of interest. Studies that did not distinguish between difference and inequity also often conflated these concepts. Altogether, this made it difficult to determine whether some studies' analytical methods were appropriate for their aims.

DISCUSSION

This scoping review aimed to describe and appraise the quantitative evidence on ethnic differences and inequities in paediatric healthcare utilisation in the UK. It found that in the last two decades, the majority of studies in this field reported ethnic variations in utilisation across a range of healthcare services. However, there was a lack of theory underpinning methodological decisions, limiting the quality of the overall body of evidence and resulting in substantial heterogeneity in the way that studies classified ethnicity. When ethnic variation was found, less than half of these studies attempted to distinguish between difference and inequity; those that did were mainly situated in primary and preventive care.

Implications for policy

In keeping with previous reviews of ethnicity and healthcare in the UK, there is a reasonably sized body of quantitative evidence on ethnic variation in paediatric healthcare utilisation across the NHS.⁶ However, within the small number of studies that found no ethnic variation, a much greater proportion attempted to identify inequities, suggesting challenges with defining research questions and methods that identify meaningful inequities, or possible publication bias in favour of studies that found ethnic variation despite not distinguishing between difference and inequity.²⁷ Furthermore, despite the long-standing and ongoing theoretical research on ethnicity and health,^{7,28} theory was rarely adopted in paediatric healthcare utilisation studies, thereby limiting the quality of studies and making it difficult to interpret and synthesise findings for policy making.

Where inequity was studied, it was most consistently done in primary and preventive care in England, owing to the large proportion of vaccination studies that could assume normative need for all children. Different underlying factors affecting vaccination access and attendance have been proposed for different ethnic groups: deprivation and parity for White ethnic groups,^{21,29} compared with barriers to accessing healthcare, timely and accessible information about preventive care and perceptions about vaccination importance for minority ethnic groups, particularly those of Black and Asian ethnic backgrounds.^{18,30,31} However, research about these underlying factors is sparse, especially for Mixed/Multiple and Other ethnic groups in the UK,³¹ likely in part due to a lack of clear definitions and inconsistencies in elicitation and reporting for these two groups.³² It highlights the need for concerted efforts to better understand how ethnic categories are conceptualised and reported in different healthcare contexts, identify why inequities occur for specific ethnic groups, and co-produce place-based actions to address them. The emergence of conflicting findings from the included studies depending on whether ethnicity was studied at an aggregate or disaggregated level also suggests that Simpson's paradox may be at play,³³ and reinforces the need to understand underlying pathways to ethnic inequities at a more granular level.

Implications for research

There are research gaps in utilisation of emergency department and outpatient services, likely due to the poorer quality and less timely release of routine health data for these outcomes compared with primary care and hospitalisation.³⁴ While improvements to emergency department and outpatient data sets could help fill these research gaps, the completeness and representativeness of ethnicity data is an ongoing concern in these two types of data sources in England as well as in other routine sources of

Table 1 Recommendations to improve the quality of research on ethnicity and paediatric healthcare utilisation

Methodological consideration	Recommendation
Theoretical frameworks	<ul style="list-style-type: none"> ▶ Avoid conflating the concepts of ethnic difference and inequity. ▶ Use theoretical frameworks to guide analysis and avoid overadjustment or unnecessary adjustment in statistical modelling.⁴⁵ ▶ Studies interested in quantifying inequities in healthcare utilisation should ensure that choice of outcomes or analytical methods account for variation in healthcare need and health outcomes between ethnic groups.⁷ ▶ Clearly define the range of normal/expected limits for healthcare use for the specific health service examined.
Ethnicity	<ul style="list-style-type: none"> ▶ Explain why ethnicity is an explanatory factor of interest and how the research will impact on the ethnic groups of interest. ▶ In the absence of universally agreed 'best' classification system for ethnicity in the UK, provide sufficient detail about the context and justification for choice of classification systems.⁴¹ ▶ Where statistical power allows, avoid aggregation of ethnic groups because the meaningfulness of interpretation of findings for policy and practice decreases with increasing aggregation,⁴¹ and aggregated estimates can mask variation between ethnic groups. ▶ When aiming to improve comparability of studies or to validate existing findings, consider using standard groupings like census groupings. ▶ Examine parent/primary caregiver ethnicity where data are available, and compare the effect of parent/caregiver ethnicity with child ethnicity in influencing paediatric healthcare utilisation. ▶ Consider the likelihood of children's recorded ethnicity changing over time in routine data sets.³⁷ ▶ Examine the potential for misclassification bias and report on the completeness and representativeness of the ethnic breakdown of study cohorts/samples.³⁵ ▶ Examine the potential for selection bias and report follow-up time by ethnic group in cohort studies. ▶ Avoid selective reporting of findings about larger ethnic groups like White, Black and South Asian when ethnic variation in healthcare use is also identified in smaller groups like Mixed and Other ethnicities.
Patterns by age, time and location	<p>Wherever statistical power allows, produce:</p> <ul style="list-style-type: none"> ▶ Age-specific estimates, particularly given the age-specific changes in healthcare utilisation rates across the life course.⁴² ▶ Year-specific estimates, or use other methods to take into account changes over time. ▶ Region-specific estimates in UK-wide or country-wide studies.

health data,³⁵ and could potentially be improved through linkages to better sources of ethnicity data (eg, census and ONS birth notification).

Though high-level data governance through NHS Digital and the ONS might allow for greater availability of routine administrative data than other countries, at the local health service level there is still much variation in the way that ethnicity and healthcare data are collected.³⁶ In the individual studies included in our review, it was not possible to ascertain how ethnicity data were elicited since almost 80% of studies used routine administrative data. Assigning ethnicity using routine administrative data poses risk of misclassification, and methods for eliciting patient ethnicity data are rarely documented; it is often a mix of self-report (gold standard), third-party report particularly in the case of children, or assumptions made by healthcare staff on the basis of sociodemographic or physical characteristics.^{36 37} Furthermore, despite the NHS's universal healthcare system with free primary care for all, access to both primary care and secondary care is an ongoing challenge for migrants in the UK,^{38 39} so routine health data and findings from subsequent studies may be less representative of individuals from minority ethnic groups who are not UK born.

Even in light of these challenges, the quality of evidence can and should be improved. We synthesised the methodological limitations of the current evidence base into recommendations in [table 1](#) to improve the validity and generalisability of future research in ethnicity and paediatric healthcare utilisation. Recommendations build on the existing work of Salway and colleagues⁴⁰ and the NHS Race and Health Observatory in the broader field of ethnicity and health research, and include further considerations for defining and classifying ethnic groups,⁴¹ using theory to guide methodological decisions,⁷ and ensuring that trends over time, by age and by location are considered. These recommendations were developed with the input of the PPI advisory group.

Strengths and limitations

To our knowledge, this is the first review to describe and appraise quantitative research on ethnicity and paediatric healthcare

utilisation in the UK, and also the first review within the field of ethnicity and healthcare more broadly in the UK to distinguish between ethnic differences and inequities. While studies of paediatric healthcare have at times excluded preventive care outcomes, we included specific search terms for preventive and avoidable care. This is because the majority of children are healthy and use healthcare services much less than older age groups with the exception of the early years,⁴² where direct healthcare contacts are likely to be for routine preventive reasons (eg, vaccinations, development checks, screening) or acute unplanned reasons.⁴³

We made a pragmatic decision to use search terms related to general healthcare utilisation of core health and medical services, rather than an exhaustive list of all healthcare and health-related services. As such, the review may not comprehensively capture services like allied health, therapies, dental, optical and pharmacy. Additionally, medication prescription was not an outcome of interest as this review focused on direct contacts with the healthcare system. Prescribing is a secondary event after contact with the healthcare system and can occur without ongoing direct contact with the system. However, prescribing is sometimes used as a measure of health resource utilisation,⁴⁴ which may limit the comparability of our review.

CONCLUSION

The majority of quantitative studies concerning ethnicity and paediatric healthcare utilisation in the UK found ethnic variations. However, ethnic inequities in healthcare utilisation that are unequal, unfair and disproportionate to healthcare needs were examined in less than half of the identified studies. While these studies provide a good starting point for policy makers, commissioners and service planners to identify services where healthcare use among certain ethnic groups is disproportionate to need, methodological challenges and research gaps still prevail. In particular, future studies on ethnicity and paediatric healthcare utilisation in the UK should provide clear parameters for classification of ethnicity and use robust theoretical frameworks to improve the validity, generalisability and comparability of research in this field.

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Contributors CXZ designed the study and wrote the paper with input from all authors. CXZ, TB and CO screened the studies. CXZ conducted extraction, appraisal and analysis with input from CC, MAQ and CB. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

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