

Equality, diversity and inclusion

Health outcomes for children and young people



Introduction

The RCPCH has begun important work in addressing equality, diversity and inclusion (EDI) within our membership. Now our commitment must also address other aspects and extend to the health outcomes of children and young people in our care. These are vital steps to work for change. Health outcomes are affected by a broad range of factors including socio-economic determinants and geographical locations. While the College has long advocated for child health equality, recent events have brought health inequality and racism front and centre: the COVID-19 pandemic and the Black Lives Matter movement. To ensure meaningful improvements in child health outcomes and to enable us to work towards ending child health inequalities, the RCPCH needs to examine the full spectrum of drivers in determining health outcomes, including ethnic background.

This report sets out the work that is already happening in the College and looks towards the future on what more can be done from building on existing work and the topics included in **health outcomes** can be seen in the diagram below.



Epilepsy12

[The National Clinical Audit of Seizures and Epilepsies for Children and Young People](#) (Epilepsy12) aims to help epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies. It currently reports a breakdown of its national clinical cohorts of children and young people with a new diagnosis of epilepsy by deprivation quintiles in order to show differences between regional networks, and variation within the overall picture for England and Wales. Epilepsy12 also reports on the type and severity of neurodevelopmental problems among the children and young people with intellectual disability, global development delay, or learning disability in England and Wales.

NNAP

[National Neonatal Audit Programme](#) (NNAP) supports professionals, families and commissioners to improve care provided by neonatal services who look after babies born too early, with a low birth weight or who have a medical condition requiring specialist treatment. The audit assesses whether babies admitted to neonatal units in England, Scotland and Wales receive consistent high-quality care, and identify areas for quality improvement in relation to the delivery and outcomes of care. Data collection currently uses maternal ethnicity data as a background variable for mortality reporting.

NPDA

[The National Paediatric Diabetes Audit](#) (NPDA) is managed by the RCPCH and collects data about the care received, and diabetes outcomes achieved, by all children and young people accessing the services of paediatric diabetes units (PDU) in England and Wales. The overarching aim of the audit is to support improvement to care and outcomes by providing reliable benchmarking data and communicating results so that they may be used as a basis to inform local, regional and national quality improvement activity. Details of the ethnic and socioeconomic inequalities highlighted in its data are outlined in the case example contained within this chapter.

BPSU

[The British Paediatric Surveillance Unit](#) (BPSU) is based at the College and facilitates rare paediatric disease surveillance. This is undertaken via an active reporting scheme called the “Orange Card”. It enables clinicians and researchers to investigate children affected by rare diseases, conditions or treatments.

State of Child Health report

The RCPCH first published the [State of Child Health](#) (SoCH) report in 2017. This was a landmark report which brought together data on a range of indicators of child health and wellbeing from across the UK, such as breastfeeding rates, immunisation coverage and child poverty, to analyse whether trends in child physical and mental health are improving, stagnating or worsening.

The most recent SoCH report was published in 2020 with new indicators added to reflect changing child health priorities and evolving challenges that children and young people face.

RCPCH &Us

[RCPCH &Us](#) is the children, young people and family network for the College, bringing together under 25s and parent/carers from different experiences and backgrounds to inform and influence our work and the child health sector. An EDI approach to being able to bring together diverse groups of children and young people to inform, influence and shape the work of the College and the sector is central to practice, with a well developed and embedded methodology within programmes.

UK Devolved Nations

The RCPCH's policy and campaigns work happens across the four [nations of the UK](#). We have additional dedicated policy and public affairs teams in Scotland, Wales and Northern Ireland to engage with national governments and other stakeholders to respond to the different landscape across the UK's devolved nations in terms of child health outcomes.

Where we are now

Research & Quality Improvements - Audits

There is potential for Epilepsy12 to undertake further analysis on the correlation between deprivation or neurodevelopmental delay, and the delivery of care and outcomes. Epilepsy12 does not currently collect or process data on the ethnicity of children and young people within its cohorts, and consideration of doing so could be explored by the project methodology and dataset group in terms of what type of associated analyses would be useful to help identify variation and drive improvement. It is noted that the small cohort size may limit the validity and reporting “power” of some of the desired additional analyses.

With agreement from the NNAP project methodology and dataset group, there is the potential for NNAP to explore conducting further analysis and reporting around inequalities in patient care and outcomes by ethnicity and deprivation. It is noted that the NNAP Project Team will require s251 approval (a legal basis from HRA CAG) to process these required identifiable data items.

There is also the potential to include data capture around ethnicity within the Patient Reported Experience Measure (PREM) component of the national audits. The dataset would need to be updated to capture ethnicity data and there would not be any possibility of conducting any longitudinal analysis for ethnicity as this data has not been collected during previous rounds of the audits.

BPSU

The BPSU collaborates with various external partners, such as university research units and research organisations to conduct studies into paediatric rare diseases. Depending on the objectives of these studies, information about patient ethnicity and sometimes Socio-Economic Status (SES) is collected. Where appropriate and in a non-disclosive way this information is published in study papers. This research is fundamental in evidencing health outcome inequalities across many areas of paediatrics affecting those with rare conditions.

For example, a [2017 study](#) into the UK incidence of nutritional rickets published in the Archives of Disease in Childhood found there was significant impact from gender and ethnicity. Of the cases that met the case definition, boys (70%) were significantly more affected than girls (30%) (OR 2.17, 95% CI 1.25 to 3.78). Furthermore, the majority of cases were of Black (43%) or South Asian (38%) ethnicity.

The BPSU does not hold patient data; this is held by an external research collaborator, so is not available to the BPSU or the College to further analyse (i.e. beyond the peer-reviewed publication). However, where research is done ‘in-house’, the data could be further investigated. Furthermore, a review could be undertaken of existing publications across all conditions to measure the extent of health outcome inequalities.

State of Child Health: Spotlight on Ethnicity

The aim of State of Child Health (SoCH) is to use data to highlight the role that social determinants of health play in the health and wellbeing of children and young people, as well as examining how an optimal environment can be created to ensure children have the best start to life. Spotlighting the health inequalities faced by children and young people in the UK enables the College to develop evidence-based policy recommendations to improve child health outcomes.

While health inequalities exist across a range of factors and characteristics, taking action to address child health inequalities by the College needs to be expanded to include an examination of the impact of ethnicity. Evidence shows health outcomes are also determined by race and ethnic minority populations are susceptible to widening health inequalities. For example, white children are more likely to get a better start in life, while children from Black ethnic groups generally have poorer health outcomes such as excess weight and higher infant mortality¹. Furthermore, the COVID-19 pandemic has highlighted that people from Black, Asian and Minority Ethnic (BAME) backgrounds are disproportionately affected by the virus, impacting upon risks and outcomes².

Therefore, incorporating a focus on ethnicity and inequalities in the SoCH is key in driving improvements in health outcomes for children and young people and the delivery of health and wellbeing services, as this is currently not reported on. However, it is important to note that the availability of health data by ethnicity is poor. For many of the indicators examined in the SoCH, ethnicity data is not routinely recorded alongside the health measurement. This results in only having a partial understanding of the factors leading to poor health outcomes as the scale of problems is not known. Without the monitoring of issues through systematic data collection, development of evidence-based policy recommendations for effective interventions is hindered.

This presents an opportunity for SoCH work to determine what ethnicity data is available to evidence the widening gap between the health of children from different ethnic backgrounds, with the aim to reduce variation in outcomes. Where the data is not available, there is an opportunity to question why there is a gap and identify who the College needs to work with to ensure comprehensive ethnicity data collection across the NHS and social care settings.

Media

An example of where the College has shown a role in supporting our policy work and championing health equality in children and young people is through our media and campaigns work. In October 2020, the College produced an open letter signed by our members to lend our voice to Marcus Rashford's school meals campaign. We knew our members care deeply about the issue and were very unhappy that the UK government refused to extend free school meals into the holiday period. We circulated a letter which was ultimately signed by 2947 paediatricians in just 48 hours. Given the strength of feeling we moved very quickly on a media plan and over the following three days, the story got 851 pieces of media coverage. There was also an outpouring of support from our members on our social media channels and our Twitter feed received 709,000 impressions over a three-day period. We published follow up pieces in the BMJ, RCPCH Insight, and ran a mini campaign in Northern Ireland.

1 Public Health England. 2017. Public health outcomes framework: Health equity report focus on ethnicity. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733093/PHOF_Health_Equity_Report.pdf

2 Public Health England. 2020. Beyond the data: Understanding the impact of COVID-19 on BAME groups. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733093/PHOF_Health_Equity_Report.pdf

Ultimately the policy was reversed, and provision of free school meals was extended. While the credit for that result belongs solely to Marcus Rashford's incredible advocacy, our members made a real difference by piling the pressure on and keeping the story in the headlines. This showed the power of the College's voice and how we can utilise our membership to challenge policy affecting the most vulnerable children and young people and tackle inequality in a meaningful way.

RCPCH &Us

Children and young people for our work is defined as infants, children, young people, young adults up to their 25th birthday and their advocates (parents, carers, families, friends, healthcare professionals, support workers – plus others) with the primary focus being supporting and encouraging the voice and views of children and young people.

Every voice and every view counts, whether it has been shared through art based activities, using communication aids for those who are nonverbal, through online responses to text consultations or in face-to-face conversations and workshops.

It is important to the work of RCPCH &Us, that we are able to work with, include and involve children and young people from a range of different experiences, ages, backgrounds, locations and specialist experiences. We have our own diversity definition that we use when planning a project, so that we can make sure we have a range of diverse voices actively involved.

Basic EDI information is collected in line with GDPR, only collecting what is going to be used as part of the project or activity. We routinely collect age and presenting gender, then depending on the programme may also collect data linked to other protected characteristics. Within work focused on health outcomes, we use the RCPCH &Us diversity methodology to support a range of voices, supporting CYP to be involved from three different cohorts:

- **Universal:** involving CYP through open access sessions where health experience is not a prerequisite for involvement e.g. schools, youth groups, outreach. Locations/settings are chosen to represent
- **Targeted:** CYP with a shared experience e.g. young carers, special school, children in care
- **Specialist:** CYP with a specific healthcare experience accessed through a health setting/ health-based condition forum e.g. clinic chat in a respiratory clinic, sickle cell forum

We aim to have all three groups involved in all pieces of work to ensure that we include as many diverse experiences and voices as possible and to prevent institutionalised bias from any one group responding. Further detail on how we ensure diverse representation can be found in the Case Study we share in the **Volunteering and Awards** workstream report.

Locations/settings are selected according to the demographic need agreed in the engagement plan for each piece of work e.g. Asthma Audit wants to hear from primary and secondary, rural and urban, mixed ethnicities, non-asthmatic and asthmatic CYP so we would then operationalise as:

- **Universal:** primary school rural/secondary school urban
- **Targeted:** special school
- **Specialist:** asthma forum, asthma clinic chat in a clinic area with a diverse population

Within the Asthma audit, most sessions included between 30-40% of responses coming from BAME communities, along with responses from young carers, children in care, those on free school meals and other groups that face inequalities.

UK Devolved Nations

To address the geographical variations in health outcomes across the devolved nations in the UK, the College responds in a number of ways. The RCPCCH have national Officers for Wales, Scotland and Northern Ireland. They are able to represent members in the devolved nations, feed into decision making within the College and provide leadership. The work of the Officers is supported by national committees for each nation, while many of the College's UK committees also have devolved nation representatives, who may not be part of the national committee. The committee members are able to inform College activity in the nations and provide insight and intelligence. In Scotland we also have the Scottish Child Protection Committee as a response to the very different child protection and safeguarding framework in Scotland.

The College has staff in each nation who are able to design policy and public affairs activity to respond to child health needs, challenges and opportunities of each nation. Staff are also able to work with other teams, for example the Workforce Team, to co-produce reports or publications and ensure that they meet the needs of each nation. These are either as separate editions for the devolved nations, as we have seen with State of Child Health and a number of workforce reports, or by feeding into UK-wide documents, as we have done a lot over the past months with policy and guidance around the COVID-19 pandemic.

Case study - consideration of ethnicity and deprivation within the National Paediatric Diabetes Audit (NPDA)

What data do we collect, and why?

The NPDA dataset, submitted annually by all paediatric diabetes units in England and Wales, is designed to measure adherence to NICE guidelines for the diagnosis and management of diabetes in children and young people.

Patient demographic information is also collected, including the patient’s ethnicity and postcode, the latter being converted during analysis to a deprivation quintile using the English and Welsh indices of deprivation. Collecting this information enables comparison of care and outcomes between ethnic categories and deprivation quintiles, which means any inequalities identified can be investigated and addressed.

What do our results show?

NPDA results have consistently shown that whilst non-White children and young people with Type 1 diabetes and those in the most deprived quintiles are not receiving fewer recommended health checks, they are more likely to have higher HbA1c. HbA1c is a measure of average blood glucose in the three months before the test. Higher values indicate suboptimal diabetes management, which increases the risk of developing diabetes related complications.

Regression analyses controlling for each demographic variable associated with HbA1c outcomes have revealed that living in a more deprived area is most predictive of poorer HbA1c outcomes, and that differences in HbA1c outcomes persist even after controlling for other demographic variables including deprivation, **with Black children and young people with Type 1 diabetes more likely to have higher HbA1c than those of other ethnicities.**

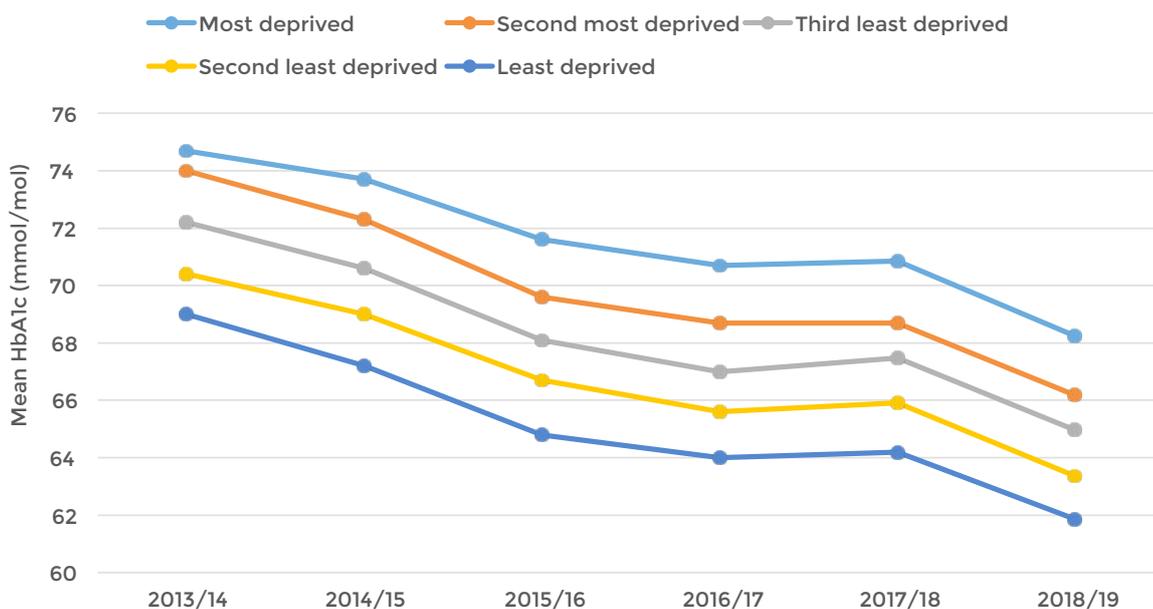


Figure 1: Mean HbA1c for children and young people with Type 1 diabetes by deprivation quintile, 2013/4 to 2018/9.

Courtesy of the Healthcare Quality Improvement Partnership 2021

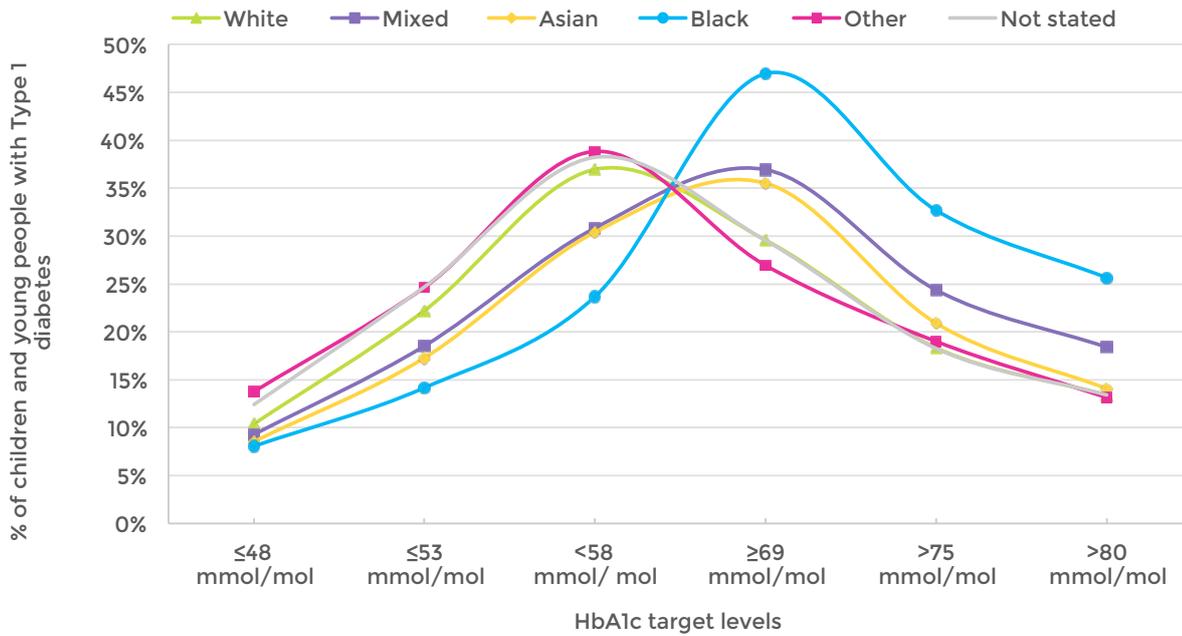


Figure 2: Percentage of children and young people with Type 1 diabetes in England and Wales achieving HbA1c targets by ethnic group, 2018/19.

Courtesy of the Healthcare Quality Improvement Partnership 2021

Figures 1 and 2 taken from the most recently published national NPDA report in 2020³ show the stark differences in HbA1c outcomes associated with deprivation and ethnicity. Figure 1 shows that despite reduction (improvement) in average HbA1c amongst children and young people with Type 1 diabetes within each deprivation quintile in every audit year since 2013/14, the association between higher deprivation and higher HbA1c has persisted.



Figure 3: Percentage of children and young people with Type 1 diabetes using insulin pump therapy within each deprivation quintile by ethnic category, 2018/19.

Courtesy of the Healthcare Quality Improvement Partnership 2021

Figure 3 from the same report shows that use of diabetes related technologies is also impacted by deprivation and ethnicity, with highest use associated with living in less deprived areas, and lowest overall use amongst Black children and young people with diabetes, irrespective of deprivation status.

How can the NPDA support improved outcomes amongst deprived or minority ethnic groups?

The most important contribution the NPDA can make to the resolution of inequalities in diabetes outcomes in children and young people is to highlight where they exist so that appropriate action can be taken. The challenge lies in establishing what the appropriate actions to take are.

Whilst these trends are evident nationally, NPDA results also show variation at clinic level, with some paediatric diabetes units achieving good HbA1c results (without case mix adjustment) despite serving a more deprived local population. Further, at the NPDA National Conference 2020, the keynote speaker Dr Gun Forsander announced that her team had been 'astonished and ashamed' to discover that ethnic minority adolescents at their clinic had poorer HbA1c outcomes compared to those of White ethnicity. Her team were able to close this HbA1c achievement gap over a period of two years by conducting a qualitative study amongst their ethnic minority patients, which established the factors influencing their ability to effectively manage their diabetes.

These examples highlight that it is possible to support children and young people from disadvantaged or minority backgrounds to achieve diabetes outcomes on a par with those of their peers and suggests that patient engagement should be at the heart of efforts to do so.

In addition to producing data to highlight where HbA1c achievement gaps exist, the NPDA has supported efforts to close it by:

- Hosting conferences at which the issue has been highlighted, and table work sessions have been held to discuss barriers faced by disadvantaged children and young people with diabetes in the self-management of the condition.
- Working with the RCPCH &Us team and Diabetes UK to conduct a series of 'clinic chats' with children and young people with young onset Type 2 diabetes and their families to understand their experiences of living with and managing the condition.

We also plan to work closely with the RCPCH Paediatric Diabetes Quality Programme and the National Network for Children and Young People with Diabetes to develop joined up strategies for:

- Engaging with children and young people from disadvantaged groups and their families to establish the barriers to achieving better diabetes management.
- Responding to the challenges identified.
- Disseminating the learning and best practice identified.

What we think is needed for the future

We have acknowledged that drivers in health outcomes are broad and the work of the College in this space is only beginning to touch the surface of this. We know that without an understanding of the full picture in drivers of unequal health outcomes, we will fail to make meaningful improvements to end child health inequalities. The following themes for further development are suggested for the College to consider in its ambitions to address EDI in its work on improving health outcomes for children and young people.

- Incorporate EDI considerations as part of the ongoing RCPCH commitment to tackle climate change. In October 2020, the RCPCH joined a coalition of organisations in declaring a climate emergency and published a plan to accelerate work in this area. Within the remit of this work, the College could, for example, scope the potential for looking at the effects of air quality and pollution on the most deprived communities.
- Examine unconscious bias in the paediatric workforce and the possible impact on health outcomes relating to differences in the quality and safety of clinical care received by particular patient groups. This could help in our understanding of the patient experience and identify areas for improvement with anecdotal evidence that patients feel more comfortable speaking to healthcare professionals of a similar background to their own.
- Separate geographical inequalities from socio-economic deprivations and examine inequalities in access to services in different areas, such as the accessibility of mental health support.
- Explore the impact of socio-economic inequalities on health outcomes in national data collection, such as greater analysis of data against regional deprivation in national audits.
- Explore what further advocacy for underrepresented CYP we push forward with in our SoCH campaigning work.

The actions we will take

As part of the ambition to broaden the scope of our work in tackling child health inequalities, we propose the following actions for the College to begin considering when undertaking work with an EDI relevance in improving health outcomes for children and young people:

Action	Date for delivery	Work led by
Acknowledge that the white ethnic group is not homogenous and sections of the community are underrepresented and disproportionately affected in health outcomes for patients. The College should begin to include this in ethnic data collection and analysis	By March 2022	RCPCH &Us team, Research and Audits team
Build on including children and young people's voice from underrepresented communities in College work, such as national audits	By March 2022	RCPCH &Us team and Audits team
Empower members to be better advocates for child health equality by building on the Ambassador programme and provide lobbying training and tools to use data and CYP voice effectively	By March 2022	Policy team and Media and Campaigns team
Undertake a scoping exercise to look at how the College's approach to parameters for health outcomes studies recognise the physiological differences in ethnicity	By March 2023	Research team and Audits team
Explore opportunities to conduct targeted research and EDI data collection in reducing health inequalities across all existing and prospective College work streams and priorities	By March 2023	Research team and Policy team
Explore what further advocacy for underrepresented CYP we push forward with in our SoCH campaigning work	By March 2022	Media and Campaigns team and RCPCH &Us team

RCPCH

Equality, diversity and inclusion. Health outcomes for children and young people

March 2021

Equality, diversity and inclusion

©RCPCH 2021

The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).

 **RCPCH**

**Royal College of
Paediatrics and Child Health**

Leading the way in Children's Health