

## COMMENTARY

# Widening health inequalities related to type 1 diabetes care in children and young people in the UK: A time to act now

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## Abstract

In this recent 2019–2020 audit, 96% (168/173) of paediatric diabetes teams submitted data and included a total of 29,242 children and young people (CYP) up to the age of 24 years, and type 1 diabetes consisted of 27,653 CYP. One of the key findings was that CYP with type 1 diabetes from minority ethnic communities have higher HbA1 compared to white ethnicity and that significantly lower use of insulin pumps or real-time continuous glucose monitoring systems was used among black children. There has been an increasing trend of widening health inequalities reported the past 6 years. As chairs of Diabetes UK Diabetes Research Study Groups, the authors urge that research into barriers of access to technology for T1D in CYP in the UK specifically looking at provider bias, systemic issues within the health system, and individual and family factors are conducted with urgency.

## KEYWORDS

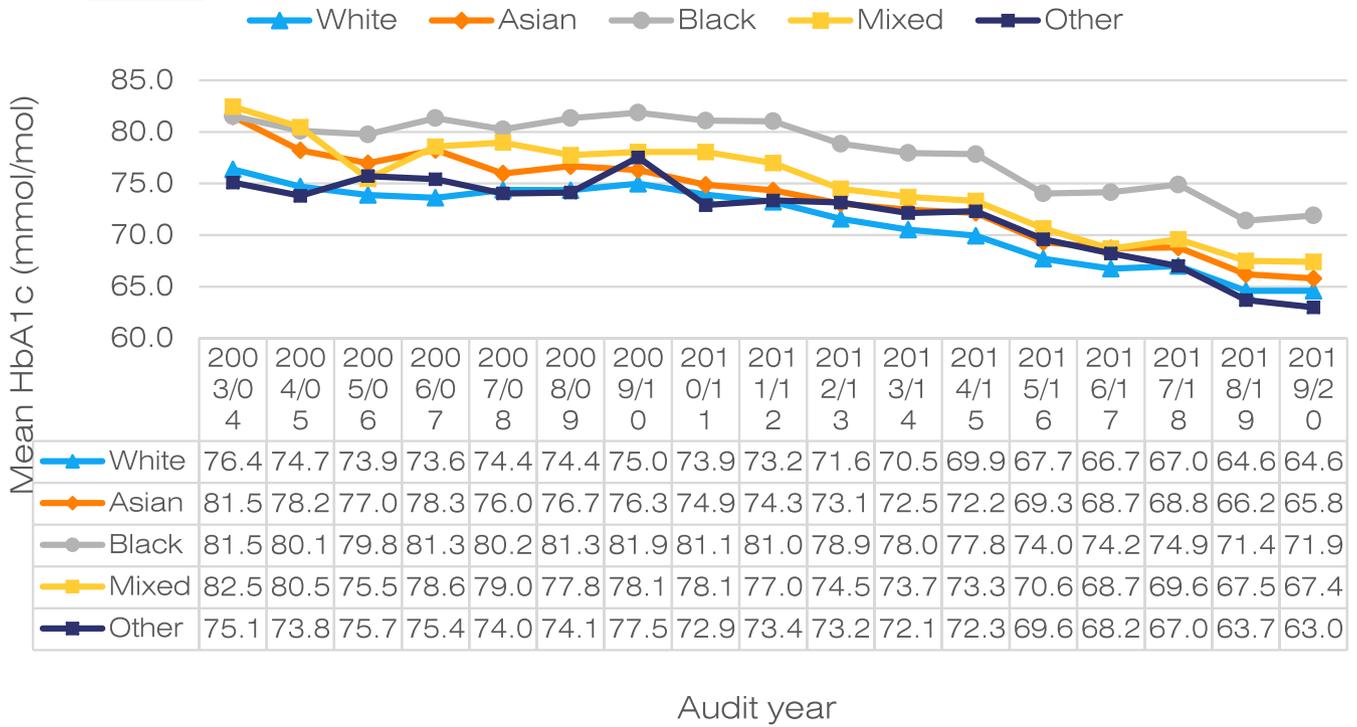
audit, children and young people, health care delivery, type 1 diabetes

## 1 | INTRODUCTION

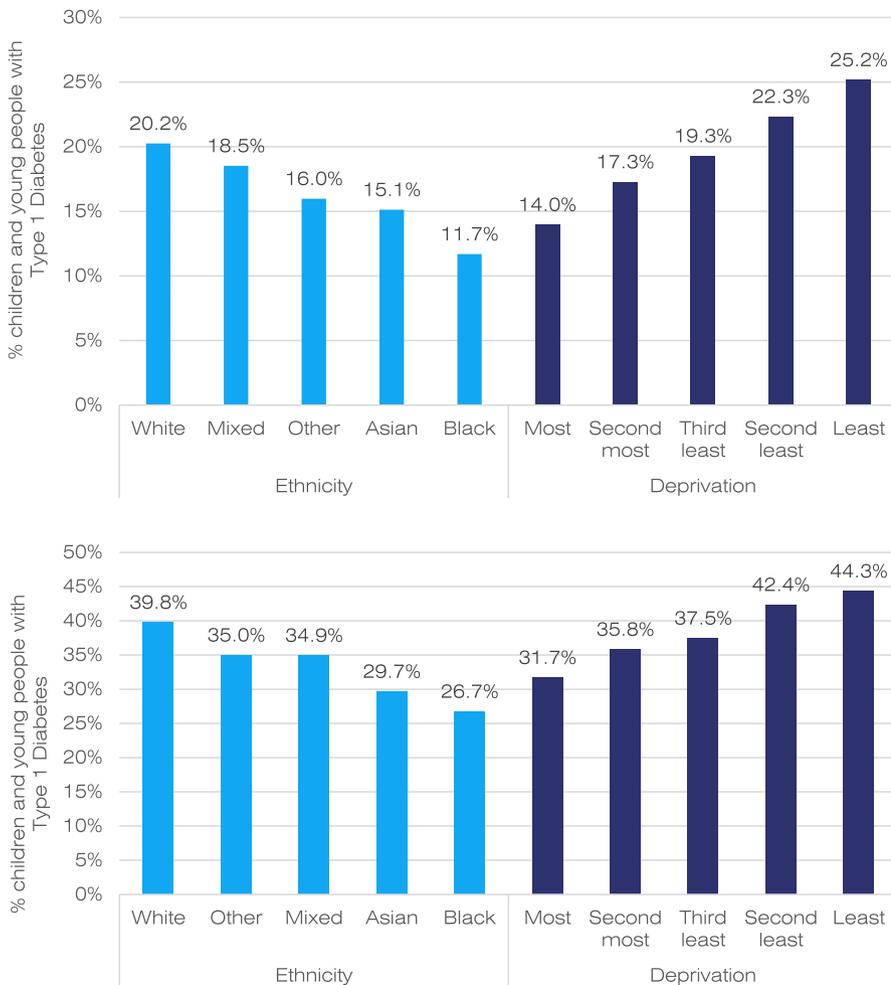
The UK has the largest prevalence of children and young people (CYP) with type 1 diabetes in Europe estimated at 193.8 per 100,000.<sup>1</sup> In 2011–2012 until 2018–2019, the National Paediatric Diabetes Audit (NPDA) had a 100% submission rate from every paediatric diabetes unit in England and Wales and reported an increase of 1.4% incidence compared to the previous year's audit. In this recent 2019–2020 audit, 96% (168/173) of paediatric diabetes teams submitted data and included a total of 29,242 children and young people (CYP) up to the age of 24 years. Type 1 diabetes consisted of 27,653 CYP and type 2 diabetes in 866 CYP.<sup>2</sup> The NPDA in the past 6 years has reported widening inequality between CYP of different ethnicity.<sup>2</sup> One of the key findings was that CYP with type 1 diabetes from minority ethnic communities have higher HbA1 compared to white ethnicity. HbA1c may overestimate mean glucose levels in black patients and about 0.4%–0.5% of disparity in HbA1c can be accounted for by racial differences in glycation of haemoglobin. In the recent 2019–2020 report, black children with type 1 diabetes

are more likely to have higher HbA1c than any other ethnic group year on year (Figure 1).<sup>2</sup>

The NPDA 2019–2020 reported that despite increases in insulin pump usage compared to insulin injections in all quintiles of deprivation, the gap between insulin pump usage among CYP living in the most and least deprived areas has widened with time in the past 6 years.<sup>2</sup> NPDA also reported significantly lower use of insulin pumps or real-time continuous glucose monitoring (rtCGM) systems among black children, whereas white ethnicity children had the highest use of pumps and rtCGM (Figure 2). Similarly, despite increases in rtCGM usage in all quintiles of deprivation, the gap between the most and least deprived areas has widened with time while the use of rtCGM was more likely to achieve lower HbA1c targets compared to those who were not using rtCGM irrespective of mode of insulin delivery.<sup>2</sup> The NPDA report also shows up to threefold differences in target glucose control achievement rates between individual Paediatric Diabetes Units (approximately 20%–60% for proportion of patients achieving HbA1c <58 mmol/mol) yet characteristics of the CYP (including ethnicity and deprivation) accounted



**FIGURE 1** HbA1c outcomes by ethnicity (from NPDA 2019–2020)



**FIGURE 2** Use of rtCGM and insulin pumps by ethnicity and deprivation (from NPDA 2019–2020)

for only 8–15% of the variation.<sup>2</sup> There remains a consistent year-on-year variation in HbA1c outcomes achieved by Paediatric Diabetes Units across England and Wales even after patient characteristics have been controlled for.

Type 1 diabetes care is complex and there is clear evidence that access to interventions and the use of diabetes technologies such as insulin pump and CGM have the potential to impact positively on health and to prevent the deterioration of glycaemic control and subsequent complications.<sup>2</sup> The use of both technologies is associated with lower HbA1c and has been shown to improve quality of life measures.<sup>2</sup> Involving CYP with diabetes in developing and using health technologies provides opportunities for enhancing their health and well-being.<sup>3</sup> Provider bias has been reported to be an important systemic factor that may play a role in barriers to access. One study reported that providers were significantly less likely to recommend more than four blood glucose checks day to African-American families compared to non-Hispanic Caucasian families.<sup>4</sup> Data from the National Clinic Registry of the Type 1 Diabetes Exchange also found that minority ethnic youths fared worse in diabetes management and were prescribed less advanced or intensive types of diabetes treatments, with caregiver perceptions of cost and provider perceptions of family competence cited as reasons.<sup>5</sup> Equitable deployment of technology may be the key barrier to glucose control improvement in type 1 diabetes but there is a dearth of randomised controlled trials and the possibility that provider characteristics other than those associated with technology deployment are equally important and needs to be addressed.

Culturally appropriate interventions such as provision of new diabetes technology that are flexible, accessible and relevant to diverse individuals and families requires a thorough understanding of both the chronic condition and the sociological context of the target population. Lipman et al described significant racial disparities in continuous glucose monitoring (CGM) and insulin pump use within CYP with type 1 diabetes despite similar rates of outpatient appointment attendance in a large tertiary centre. While cultural factors such as differences in the perception of what constitutes good management may be contributory, the authors noted that implicit racial and ethnic bias among healthcare professionals may also contribute to disparities in the treatment and outcomes of minority patients.<sup>6</sup>

In a study by Farrington et al, clinicians were found to exhibit a range of opinions and attitudes towards eligibility to closed-loop technology access for type 1 diabetes.<sup>7</sup> Technology adoption and equitable uptake should be dependent on robust implementation pathways; otherwise, there is a risk of clinicians drawing on informal criteria to limit or expand access, as with current insulin pumps and CGM technologies. Lawton et al explored in-depth, health professionals' perceptions of the types of individuals who would

be most likely to gain clinical benefit from using an insulin pump and found significant attitudinal barriers and prejudicial assumptions among staff about who is able to make effective use of insulin pumps.<sup>8</sup> Lawton et al in another study also concluded that prejudicial assumptions existed among healthcare professionals on decision making for access to closed-loop technologies and to ensure fair and equitable access to closed-loop systems, clinical guidelines and pathways need to be made available in a timely manner.<sup>9</sup>

To date, there is limited research into the challenges or barriers of using diabetes technology and concerns felt by end-users. The views of CYP with diabetes are often under-represented in the literature while healthcare professionals' attitudes are currently a neglected aspect of this dilemma. In the recent paper by Lavizzo-Mourey et al<sup>10</sup> this month, factors that underpin health inequalities are deconstructed and health researchers and policymakers are also encouraged towards looking at root causes systems of structural racism such as barriers to economic mobility, access to high-quality education and healthcare and policies that allow racial inequalities to persist.

Successful technology adoption in healthcare is dependent on a range of factors where stakeholder perspectives are taken into account. A sixth consecutive year of significant health disparities and worsening access to diabetes technology based on ethnicity and deprivation in CYP are now reported in the NPDA. As chairs of Diabetes UK Diabetes Research Study Groups,<sup>11</sup> we urge that research into barriers of access to technology for type 1 diabetes in CYP in the UK specifically looking at provider bias, systemic issues within the health system, and individual and family factors are conducted. The increasing trend of widening health inequalities year on year is unacceptable.

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