# Improving access to diabetes care and education within Travelling communities

## Claire Vine

While more than 4.3 million people in the UK live with a diagnosis of diabetes, a further 2.4 million people are at high risk of developing type 2 diabetes. Diabetes prevalence in Travelling communities is unclear, partly owing to the way that practices record ethnicity. This population faces many challenges, including social isolation and discrimination from wider society, and a range of barriers to healthcare access. This article outlines an outreach pilot project in Essex designed to improve access to diabetes services and screening for these communities. The pilot was successful in conducting 14 diabetes healthcare checks in one day, and was able to refer other health concerns onward for review. Although there is much work still required to improve inclusion for Travellers in diabetes care, the project represents a positive starting point.

hile we know that diabetes now affects over 5 million people in the UK (Gregory, 2023), the significant barriers to screening and monitoring faced by those within close-knit Travelling communities make it difficult to establish the prevalence of diabetes within this population. This is compounded by the lack of opportunities to self-identify in the NHS Data Dictionary.

Although the evidence is limited, it is likely that most of those with diabetes within Gypsy and Traveller communities have type 2 diabetes. In this group, ill health is often seen as an inevitable consequence of adverse social experiences, and is fatalistically accepted as part of the ageing process (Van Cleemput et al, 2007). We know that the Traveller population is one of the most disadvantaged groups when it comes to accessing health and well-being needs, and there is a pressing need to find out how to support and improve access to services for this cohort.

While reliable sources estimate a UK Traveller population of around 300000 (Waters, 2016), in

England and Wales only 57 680 people identified as being of Gypsy or Irish Traveller ethnicity in the 2011 Census (Office for National Statistics, 2014). Reluctance to disclose their ethnicity may be due to fear of discrimination (Waters, 2016), but not knowing the population and its concerns makes it difficult to plan and develop health services.

In Essex, local councils have been exploring ways to help improve health for the residents living on Traveller sites. In the Borough of Thurrock in the south of the county, the most recent assessment identified 18 Gypsy and Traveller sites, with 133 pitches (a pitch providing for one "family unit"; Opinion Research Services, 2018).

To support Travellers' social health and well-being, the local council has employed Traveller liaison officers and assistant Travellers' wardens. They offer support to Travellers with:

- Registering with a doctor and dentist.
- Accessing primary immunisations and flu jabs.
- Accessing treatment for long-term conditions.
- Healthy eating and smoking cessation.
- Accessing antenatal care.

**Citation:** Vine C (2024) Improving access to diabetes care and education within Travelling communities. *Journal of Diabetes Nursing* **28**: JDN319

#### **Article points**

- The Traveller population is one of the most disadvantaged minority groups in the UK and they face multiple barriers to healthcare access.
- A high prevalence of diabetes exists in the Traveller population in Essex. An outreach pilot project was developed to improve access to diabetes services and screening.
- A health bus visited a Traveller site from which health checks, including retinal screening, were conducted.
- 4. The pilot project was successful in reducing barriers between Travellers on the site and the healthcare professionals, while delivering muchneeded diabetes care.

#### Key words

- Access to healthcare
- Health education
- Travellers

### Author

Claire Vine, Community Diabetes Specialist Nurse and Queen's Nurse, Mid and South Essex NHS Foundation Trust. "By using a venue next to a Traveller site, it was possible to break down barriers, engage the community and build trust in an environment that was familiar to them." After establishing relationships with some of the Traveller families, they noted that a high proportion of people already had a diabetes diagnosis or were concerned that they may have it. In Mid and South Essex, there are approximately 61 300 people living with diabetes – around 5300 with type 1 and 56000 with type 2 diabetes (Mid and South Essex Health and Care Partnership, 2020).

The Diabetes Health Bus Service project was subsequently developed and piloted. Funding to create an outreach team to make the most relevant health and social care information and services more accessible to communities was sourced from public health funds and the NHS.

#### **Pilot study**

At the start of the project, Traveller liaison officers built relationships with prominent people within the local area's Travelling communities. However, owing to the continuing existence of social barriers, it was not possible to access all of the communities. A lack of trust and an unwillingness to engage is the inevitable result of the high level of prejudice, hostility and social stigmatisation that they face, the unwillingness of wider society to accept their way of life and the lack of understanding of their cultures.

Gypsies and Travellers continue to face high levels of racial discrimination, which contributes to and exacerbates the inequalities they experience. A range of factors, such as poor accommodation, frequent address changes, poor health literacy, and a lack of cultural awareness and understanding by health professionals, create barriers to accessing healthcare (Cromarty et al, 2019).

For this project, Thurrock Council was able to hire a health bus commissioned by a neighbouring local authority and funded through the NHS and public health. It still required staff and other practical elements, such as an electricity supply, but the Traveller liaison officers reached out to the local primary care services and diabetes specialist teams for help. The Travelling communities welcomed the bus and staff into their various sites across the Thurrock area.

A standard operating procedure was created by the diabetes specialist team to establish how the health checks and education would be conducted, and visiting dates were agreed with the different travelling sites across Thurrock. The health check would include a blood pressure measurement and a random blood glucose test. Education would be provided on preventing type 2 diabetes through identifying risk factors, such as BMI, mental health and hypertension. Literature on diabetes and how to manage mental health would be available to take away, and basic information for a healthy diet promoted.

The first session, with a diabetes nurse specialist and a diabetes associate practitioner was organised from 9 a.m. to 3 p.m. The session was a one-off pilot, and was held in a garden centre on privately owned Traveller land next door to the entrance of the Traveller site. The bus visit was advertised on social media and spread by word of mouth through the local community. On the day of the pilot, the Traveller liaison officers knocked at people's homes on the site to encourage attendance, and drove people they knew on the site to the bus if their mobility was poor. During the pilot, 14 people from the site, with a range of health problems, attended the health bus. At least ten were at risk of, or already had, diabetes. Where required, onward referrals were made for health concerns.

## **Reflections on the pilot study**

At the end of the pilot, a debrief was arranged with the professionals involved in order to evaluate and discuss the future prospects of the project. It was felt that publicity on social media was the best method to use for this population, and that the location was excellent. It was based at the access point to the Traveller site and there were good, secure facilities for the clinicians, such as toilets and an electricity supply.

The health bus was an extremely convenient way to provide healthcare to our patients' doors. By using a venue next to a Traveller site, it was possible to break down barriers, engage the community and build trust in an environment that was familiar to them.

It was felt that means of communication could also be adapted to suit all reading ages, as low levels of literacy amongst the adult population present a barrier to accessing information. The bus equipped the health professionals to provide confidential verbal information and printed health literature, and to undertake the majority of the nine diabetes care processes (NHS RightCare, 2018).

As they did not have access to shared data, the clinicians were unable to search for when participants' last HbA<sub>1c</sub> or cholesterol

measurements were completed. Nor were they able to take blood or urine samples. However, measuring blood pressure, height, waist, weight and BMI, and conducting mental health and retinal screening, were all achievable.

Initial discussions about this pilot included whether one or two diabetes specialist nurses (DSNs) were required. On reflection, two members of the team were absolutely required, but having one DSN and an associate practitioner (AP) provided an enhanced skill mix and a cost saving. The AP was able to undertake examinations, such as for weight and blood pressure, and offer essential diabetes education on diet and lifestyle, while the DSN was able to deal with more complex issues. Although the Traveller participants were attending for a diabetes check-up, other concerns that were raised, such worries about menopause and undiagnosed health conditions, required the DSN to offer general advice and ensure that a follow-up with a GP was booked.

As well as the specialist diabetes team, a host of specialities were involved in the pilot. These included mental health practitioners, and wellbeing, retinal screening and local lifestyle support services. All were part of the initial scoping and planning of this project, and were key to its success.

Having access to all these services at once meant that people were more willing than usual to come along and engage with services. For example, there is evidence that the uptake of mental health services by Travellers is low, as there is a strong stigma associated with having mental health problems within these communities. As well as experiencing racism and discrimination, Travellers face a range of stressors, including a shift from their traditional lifestyle, poor living environments, worry and bereavement (Walker, 2008). This can lead to feelings of being socially outcast and to low selfesteem. On top of all this, people with diabetes experience excessively high rates of depression, anxiety and eating disorders (Diabetes UK, 2023). Diabetes UK recommends that everyone with diabetes should have access to psychological treatment and support to reduce psychological distress and improve self-management (Diabetes UK, 2023).

The retinal screening service was also well attended. Screening is recommended for people with diabetes aged 12 years and above (NHS England, 2022). Retinal screening was conducted for any participant who had not previously attended or who was overdue for screening.

Facilities on the bus allowed the clinicians to conduct a random finger-prick test for diabetes risk, blood pressure measurement, waist measurement and BMI calculation. The environment on the bus also offered a secure safe space to discuss other health concerns, including problems with mental health.

Part of the initiative's aim was to improve access to diabetes care for people from the Travelling community and to build trust with healthcare professionals. The local GP surgeries were invited to take part in the pilot but, unfortunately, they were unable to attend due to work demands and pressures. This left a void for attendees who needed to discuss their current diabetes management and other concerns with a GP.

Another problematic finding was that local GPs rely on QOF data, but no shared care was obtained before the planned event. This led to the DSN not being able to record QOF data on the patients' notes, as the correct coding was required. There was also some difficulty in contacting the GP surgeries during the session to arrange follow-up consultations.

The opening pilot was to provide the health bus between 9 a.m. and 3 p.m. This was mainly led by the community whose electric was being utilised for the health bus but, on reflection, these timing were not ideal. The men who attended were on their way to or from work, and the majority of the footfall was between 10 a.m. and 1 p.m. It is felt that the timings should have been earlier or later in the day to capture those people who were working. Of those visiting the bus, around 70% were male. This high proportion may have been due to the accessibility of the bus. It was situated at the entrance to the site, along a busy road that was not child-friendly for mothers who wanted to attend.

While there was a range of healthcare professions available during this pilot, including mental health practitioners, nurses, healthcare assistants and health and well-being coaches, the majority of them decided to take a door-to-door approach. As a consequence, those participants who attended the bus missed out on discussion and education from the health professions who were involved in outreach. This led to extra pressure being exerted on the DSN and AP, who tried to promote the other services.



# Meeting the healthcare needs of Travellers with diabetes

Margaret Greenfields discusses the barriers and solutions to working with this group in order to support them in managing their condition.

Journal of Diabetes Nursing 18: 193–8

Read it here

"Significant savings in both human suffering and financial cost could be made if the barriers to screening that these communities face are addressed."

The health bus was very compact and only limited supplies could be stored on it. The health literature that was taken to give out was not adequate in a number of ways. While all of the participants that attended referred to diabetes as "sugar diabetes", the literature used different terms and language. In the local area, 23% of the population in this area have a low literacy or numeracy level (Stevenson et al, 2022). The research also suggests that 45% of the Travelling community has no or poor literacy (Holmström, 2019). This meant that education needed to be delivered verbally, which took considerably more time than providing literature. A quick health check turned into a 30-minute consultation but, with the weather against us, people arriving did not want to wait. People could also have been deterred by the lack of seating in the waiting area.

#### **Future considerations**

Because of inequalities in the education system, a disproportionate number of people in these communities have low or no literacy. Without support, they find it find it difficult to read medical letters, access services and obtain key information (Friends, Families & Travellers, 2023).

This project highlighted that diabetes health literature for Travelling communities is a key area in which improvement is required. Currently, there is no literature readily available that is written for this population. Careful consideration should be given to the format in which it is available and to its cultural appropriateness. The local diabetes service in the pilot area currently delivers group education. This education could be adapted to suit the needs of the Traveller community, and provide information using physical and verbal communication rather than in written format.

The health bus timings need to be reconsidered for future ventures. Diabetes is not a Mondayto-Friday condition and, with approximately 1000 residents on the pilot site, 14 participants was a small uptake. In view of this, diabetes health screening needs to be trialled at other times of day or, possibly, at the weekend. The difficulties will include cost implications and service support from healthcare professionals, such as GPs, who may not currently work during these hours.

There is great potential to assist with admission avoidance. It has been reported that often Gypsies

and Travellers will present themselves at a very late stage of quite significant illness, so early intervention could make a huge difference to health outcomes (Office for National Statistics, 2022). With the grave complications associated with diabetes, such as amputations and cardiovascular events, significant savings in both human suffering and financial cost could be made if the barriers to screening that these communities face are addressed.

- BBC News (2022) Irish Travellers 'mental health crisis' driven by discrimination and deprivation. BBC, London. Available at: https://www.bbc.co.uk/news/world-europe-61117469 (accessed 26.0.1.24)
- Cromarty H, Kennedy S, Powell A et al (2019) *Gypsies and Travellers* (Briefing paper 08083). House of Commons Library, London. Available at: https://commonslibrary.parliament.uk/ research-briefings/cbp-8083 (accessed 26.01.24)
- Diabetes UK (2023) Number of people living with diabetes in the UK tops 5 million for the first time. Diabetes UK, London. Available at: https://bit.ly/48JhQhU (accessed: 26.01.24
- Friends, Families & Travellers (2023) Advice for GP surgeries: Providing an inclusive service to Gypsies, Travellers, and Boaters. Friends, Families & Travellers, Brighton. Available at: https://www.gypsy-traveller.org/general-practice (accessed 26.01.24)
- Gregory A (2023) *UK in 'rapidly escalating' diabetes crisis as cases top 5m*. The Guardian, London. Available at: https://bit.ly/3SFNPKu (accessed 26.01.24)
- Holmström R (2019) Understanding health needs of the Traveller community. The Royal College of Physicians, London. Available at: https://www.rcplondon.ac.uk/news/understanding-healthneeds-traveller-community (accessed 26.01.24)
- Mid and South Essex health and Care Partnership (2020) *Diabetes:* prevention and Mid and South Essex HCP Framework. Available at: https://democracy.southend.gov.uk/documents/s40770/ Diabetes%20Covering%20Report.pdf (accessed 29.01.24)
- NHS England (2022) Your guide to diabetes eye screening. Available at: https://bit.ly/3SxQrK4 (accessed 26.01.24)
- NHS RightCare (2018) NHS RightCare Pathway: Diabetes. Available at: https://bit.ly/3SEGzyp (accessed 26.01.24)
- Office for National Statistics (2014) 2011 Census analysis: What does the 2011 Census tell us about the characteristics of Gypsy or Irish travellers in England and Wales? ONS, London. Available at: https://bit.ly/3ShkkNH (accessed 26.01.24)
- Office for National Statistics Census (2022) Gypsies' and Travellers' lived experiences, health, England and Wales: 2022. Qualitative research exploring the lived experiences of Gypsy and Traveller communities, relating to health. ONS, London. Available at: https://bit.ly/42u07Hr (accessed 26.01.24)
- Opinion Research Services (2018) Essex, Southend-on-Sea and Thurrock Gypsy, Traveller, and Travelling Showpeople Accommodation Assessment Summary 2016–2033. ORS, Swansea. Available at: https://www.rochford.gov.uk/media/2773 (accessed 26.01.24)
- Stevenson A, Wong M, Evans S (2022) New analysis shows huge disparity in adult literacy and numeracy which must be tackled to boost levelling up. Learning and Work Institute, Cardiff. Available at: https://learningandwork.org.uk/news-and-policy/ literacy-numeracy-england-map (accessed 26.01.24)
- Van Cleemput P, Parry G, Thomas K et al (2007) Health-related beliefs and experiences of Gypsies and Travellers: A qualitative study. J Epidemiol Community Health 61: 205–10
- Walker MR (2008) Suicide among the Irish Traveller Community 2000–2006. Wicklow County Council, Wicklow. Available at: https://www.paveepoint.ie/wp-content/uploads/2014/01/ Suicide-among-Travellers-Mary-Rose-Walker.pdf (accessed 26.01.24)
- Waters J (2016) *Gypsy and Roma Travellers: Joint Strategic Needs Assessment.* Public Health Kingston, Kingston upon Thames. Available at: https://bit.ly/49h3DZk (accessed 26.01.24)