

# It's a sweet life travelling: Meeting the healthcare needs of Travellers with diabetes

*Margaret Greenfields*

**Romany Gypsies and Irish/Scottish Travellers are amongst the oldest established minority ethnic groups in the UK and studies have indicated a high incidence of diabetes in these populations. This article discusses the health behaviours and lifestyles common to these communities, whether nomadic or housed. These factors impact on causation, diagnosis, self-care and access to treatment. The article also considers the nature of the sometimes problematic relationship that can exist between healthcare professionals and Gypsies and Travellers, and discusses policy approaches to enhancing population health. Nurses involved in the care of Gypsies and Travellers with diabetes can find information about the barriers and solutions to working with this group in order to support them in managing their long-term condition.**

Romany Gypsies and Irish/Scottish Travellers are amongst the oldest established minority ethnic groups in the UK, with records of their migration, nomadism and presence in Britain dating back centuries (Clark and Greenfields, 2006). Although the populations are typically considered together for the sake of policy convenience and they are all recognised as ethnic minorities protected under the Race Relations Act (1976), each of these communities has a distinct ethnic and cultural background. Irish and Scottish Travellers, whilst their origins are unclear and subject to debate, are essentially nomadic populations who are “indigenous” to Britain and Ireland, both of whom have a long history of migration between the various countries of the UK. Romany Gypsies, however, are a people of Indic origin, closely related to European Roma people, who are known to have first migrated to Britain some six hundred years ago (Mayall, 1995), retaining a presence in the country ever since.

For a relatively small population (believed to number no more than 300 000), Gypsies and Travellers have been subject to a remarkable degree

of public policy intervention and concern over recent years (Cemlyn et al, 2009), much of which has been concentrated on high profile issues of accommodation shortage for those who wish to remain living in caravans on sites; sedentarisation policies, and the move away from travelling to “enforced settlement” (Smith and Greenfields, 2013). As a result of increased urbanisation, declining opportunities for nomadic employment and the difficulties inherent in accessing caravan sites, there has been a dramatic change in population behaviours in little more than a generation (Ryder and Greenfields, 2010); it is now calculated that around two thirds of Gypsies and Travellers live in housing (Department for Communities and Local Government [CLG], 2012), and of those who remain caravan dwellers, approximately 80% live at residential Gypsy and Traveller caravan sites (CLG, 2013). The remaining small percentage of Gypsy and Traveller households, calculated to comprise around 3 400 families in total (CLG, 2013), are the population who remain the most at risk of premature mortality and morbidity across all health domains.

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## Article points

1. Romany Gypsies and Travellers are amongst the oldest established minority ethnic groups in the UK and studies have indicated a high incidence of diabetes in these populations.
2. Research suggests that these groups have poorer diets, lower levels of exercise and an increased risk of depression. Specific barriers, such as low levels of literacy and diabetes knowledge, can prevent Gypsies and Travellers with diabetes from getting the best possible care.
3. Diabetes nurses can also improve the care of people with diabetes by taking time to get to know local community members and spending time with specialist staff who have already built up knowledge and relationships.

## Key words

- Access to healthcare
- Gypsies
- Health education
- Travellers

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### Page points

1. Regardless of their accommodation type, or ethnicity, members of the travelling community are repeatedly found to experience disproportionate diagnoses of diabetes and other preventable conditions.
2. Anecdotally, the overwhelming majority of diabetes cases found amongst these communities are of people with type 2 diabetes, and respondents to studies commonly regarded it as a natural process of reaching middle-age.
3. There is little specialist research that has been undertaken in relation to diabetes amongst the travelling community.

Regardless of their accommodation type, or ethnicity, members of these communities are repeatedly found to experience disproportionate diagnoses of diabetes (Saunders, 2007; Matthews, 2008) and other preventable conditions that impact on their health and wellbeing.

### The general health status of Gypsies and Travellers

Among those practitioners and health policy professionals who work in the field of inclusion health (Social Inclusion Task Force, 2010) it is widely recognised that Gypsies and Travellers experience some of the poorest health outcomes of any groups in the UK (Parry et al, 2004; Cemlyn et al, 2009). Indeed in 2013, the Office for National Statistics reported that Gypsy/Irish Traveller respondents had the highest proportion of people claiming “Not Good” general health (29.8%) of any ethnic group included in the 2011 census. This finding is disappointing but unsurprising, as a range of existing studies demonstrate increased premature mortality (Baker, 2005) and greatly exacerbated rates of morbidity amongst these populations (Matthews, 2008), with diabetes, cardiovascular conditions and respiratory problems particularly implicated in rates of long-term limiting illness or disability amongst these communities. In addition, Parry et al (2004) found that high rates of miscarriage, stillbirth, neonatal death and premature death of children were reported by female Gypsy and Traveller respondents.

There is also abundant evidence to suggest high rates of depression and anxiety in these populations, particularly amongst those living in housing who were previously resident on caravan sites and who report loss of community and isolation as a result of making the transition into “bricks and mortar” (Parry et al, 2004; Goward et al, 2006; Cemlyn et al, 2009; Smith and Greenfields, 2013).

A useful review of clinical information/data sources on hard-to-reach groups concludes that there is a pressing need to identify the main burdens of morbidity and mortality amongst vulnerable groups, including Gypsies and Travellers, in order to provide a focus on areas where data capture will be most important to improve health outcomes, and in assessing where service delivery and monitoring should be prioritised (Aspinall, 2014). This article, which sets out to summarise the particular health

risks and behaviours common to Gypsy and Traveller populations, as well as the barriers they face to accessing primary and secondary care, considers how best DSNs can work with their colleagues, service users from these populations and clinical commissioners to bring about long-term health change and reduce the “ethnic health penalty” (Salway et al, 2013).

### Diabetes in Gypsies and Travellers

There is very limited published evidence that differentiates between type 1 and type 2 diabetes amongst Gypsy and Traveller communities. Anecdotally, however, the overwhelming majority of cases found amongst these communities are of people with type 2 diabetes, and respondents to studies commonly regarded it as a natural process of reaching middle-age, supporting Van Cleemput et al's (2007) assertion of a fatalistic attitude towards poor health amongst members of the populations.

Whilst Parry et al (2004) found limited variation in diabetes rates between their sample and other ethnic groups, Saunders (2007) reported a high prevalence of diabetes amongst Gypsies and Travellers, and very limited knowledge of risk factors or implications. Secondary analysis of large-scale administrative data sets (Greenfields, 2009) found that in some localities, up to 14.6% of Gypsy/Traveller respondents reported that they had diabetes, compared with a range of 5.3–6.7% of the population across the United Kingdom in 2013. A more recent health needs assessment (Greenfields and Lowe, 2013) found that 17–20% of Gypsy and Traveller respondents (varying by specific ethnic groups) reported having diabetes.

Despite the consistency of these findings and supporting comparative data that indicates these populations experience much poorer health outcomes and a considerably greater burden of preventable disease (Parry et al, 2004; Office of National Statistics, 2013), it is surprising how little specialist research has been undertaken in relation to diabetes amongst these communities.

### Lifestyle and health-seeking behaviours

Of the limited research reports that have a particular focus on people with diabetes from the Gypsy and Traveller communities (Saunders, 2007; Roberts et al, 2007), all existing studies have

consistently found that respondents report unhealthy and sedentary lifestyles, high rates of obesity and limited awareness of healthy eating patterns. Roberts et al (2007), in their outreach project in Wrexham, noted that when compared to a control group of residents from a deprived local area, the Gypsy and Traveller respondents had a significantly poorer diet, particularly in relation to consumption of fruit and vegetables, far lower levels of exercise and greatly increased rates of anxiety and depression.

Greenfields and Brindley (in press), in a report on the impact of accommodation on health, found high levels of depression amongst both housed and insecurely sited respondents, which is likely to impact on dietary habits. For example, a number of individuals reported appetite disturbances caused by stress or physical evictions; whilst other interviewees commented on the difficulties in accessing shops with a range of food when living at remote locations, or in environments where they had limited access to food storage or outside space.

The Traveller Women's health project piloted at Buckinghamshire New University (Greenfields and One Voice for Travellers, in press) delivered modules on healthy eating to women participants undertaking a programme of health advocacy training. During discussions on sugar and salt intake, all eight participants referred to having relatives who had diabetes and indicated that the vast majority of Gypsies and Travellers they knew had poor knowledge of the causes and prevention of diabetes. Furthermore, women reported that convenience foods were eaten regularly, not only as this is the preferred diet (particularly amongst men and children) but also due to financial and practical problems associated with feeding a number of people at one time, as well as problems storing fresh food in cramped accommodation.

With the decline of traditional physical employment activities in this population, increased use of motor vehicles instead of walking alongside horses and a decrease in healthy eating, which historically would have consisted of fresh-picked vegetables and lean meat, there has been a disproportionate impact on health behaviours and outcomes for these ethnic groups within a very short time-frame; portion sizes have also typically remained the same as when engaged in more physically demanding activities (Greenfields, 2009). Moreover,

there is anecdotal evidence that Gypsy and Traveller women experiencing depression and social isolation in housing or "snacking" whilst caring for their children are consuming a large number of high-calorie treats or sugary drinks. Some practitioners have also indicated that sugary foods are given to children as a norm from a very young age, and that families may regard refusing a child such "titbits" as tantamount to withholding love (Dion, 2008). Greenfields and Lowe (2013) interviewed dentists in the North Somerset health needs study who reported that they had treated very young Traveller children with dental cavities as a result of a high-sugar diet. Therefore, there is an urgent need to improve education about healthy diet among these populations.

### Encouraging behaviour change

Whilst there is abundant evidence showing the lifestyle patterns that are implicated in the high rates of diabetes amongst Gypsies and Travellers, there may be specific challenges involved in terms of encouraging lifestyle change and early diagnosis of the condition for community members.

Parry et al (2004), supported by findings from Saunders (2007), Matthews (2008), Dion (2008), Cemlyn et al (2009) and Greenfields and Lowe (2013), stress that Gypsies and Travellers may experience significant institutional barriers to accessing preventive screening services or primary care. All of the studies mentioned previously, as well as a number of local health needs assessments undertaken around the country, have found that some GPs may be reluctant to accept patients perceived of as mobile, resource intensive or "difficult", leading to diabetes remaining unidentified. In addition, there are consistent reports by practitioners, supported by research (Van Cleemput et al, 2007; Matthews, 2008) that health professionals' communication styles can be seen as patronising, dismissive of cultural practices, or racist by Gypsies and Travellers.

The use of medical jargon or expectations of literacy (which is significantly lower than amongst main-stream populations; Cemlyn et al, 2009), or an assumed familiarity with medical systems can all place hurdles in the way of individuals obtaining treatment or access to screening. One major source of conflict reported by both Gypsies and Travellers and health professionals is a differing expectation over

### Page points

1. Outreach work in Wrexham found that Gypsy and Traveller respondents had a poorer diet, lower levels of exercise and greatly increased rates of anxiety and depression compared to a control group of residents from a deprived local area.
2. With the decline of traditional physical employment activities in this population, increased use of motor vehicles instead of walking alongside horses and a decrease in healthy eating, there has been an impact on health behaviours and outcomes for this population.
3. Research has indicated that Gypsies and Travellers may experience significant institutional barriers to preventive screening services or accessing primary care.

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1. Differing expectations between healthcare professional and Gypsies and Travellers over how appointments should be used have been reported. For example, some patients attend appointments with extended family groups with a variety of medical problems and this can cause anxiety in the practitioner.
2. Word-of-mouth recommendations have an important role in Gypsy and Traveller communities and often a bad experience with one individual can lead to other members of the community avoiding appointments with a particular healthcare professional.
3. Specialist outreach diabetes care could potentially be provided by a multidisciplinary team of community health nurses engaging with "roadside Travellers".

how appointments should be used (Van Cleemput, 2012). For example, extended family groups with a variety of medical problems, or mothers with a relatively large group of children, may turn up to an appointment together in a way that seems noisy, aggressive and chaotic to practitioners. This can cause anxiety in a practitioner and a desire to keep the consultation as short as possible. Similarly, individuals who are not registered with a GP, who cannot obtain an early appointment, or who are seeking a second opinion, may attend A&E, meaning that only the presenting symptom rather than underlying conditions may be identified.

Research is almost unanimous in agreeing the importance of word-of-mouth recommendation amongst Gypsy and Traveller communities to the extent that a bad experience with a healthcare practitioner can lead to a surgery or practitioner being avoided or mean that treatment is not sought by someone with a major health condition, for fear of being humiliated or patronised (Matthews, 2008; Van Cleemput, 2012; Greenfields and Lowe, 2013). Similarly, a healthcare provider who is recognised as "understanding" Travellers, or who has a good reputation for patience, may find that individuals from these communities will travel for many miles to see them, often remaining registered at a practice, even if they are now a considerable distance from their former home, perhaps through using "care of addresses" (such as the home address of friends and family locally resident) as a way of accessing care from their favoured nurse or medical team (Parry et al, 2004; Greenfields and Lowe, 2013). One highly experienced diabetes nurse interviewed by the author in 2013 reported that she had been told how Gypsy and Traveller patients would attend the surgery to ask if she was on duty and if she was not there, or they were unable to obtain an appointment with her, would refuse to see any of her colleagues, preferring to come back on another occasion. She said:

*"They trust me, and they know I've been here long enough that I'm not going to disappear off any time quickly. It takes a long time to build up trust and respect."*

The value of cultural awareness and being recognised as "trustworthy" cannot be over emphasised; in hurried appointments that are

uncomfortable or tense, it is unlikely that an individual who may have diabetes will feel confident to discuss minor but indicative symptoms, or explain that they have difficulties in being compliant with treatment. Where individuals are functionally illiterate (an estimated 40% of the Gypsy and Traveller population; CLG, 2012), the stigma attached to acknowledging an inability to read instructions can lead to acute difficulties asking for advice about diet and use of diabetes medication. One woman who participated in the Health Advocacy Project (Greenfields and One Voice for Travellers, in press) reported that her mother-in-law who had diabetes and who could not read, always had to go shopping with a literate family member in order to ensure that she was aware of the sugar content of food purchased. This woman noted (to general agreement) that traffic-light labelling, or a card that showed images of low-sugar or diabetes-suitable food would be a helpful way of identifying healthy products.

### Nomadism, evictions and the impacts on health care

As mentioned previously, whilst a relatively small percentage of Gypsies and Travellers are technically homeless (for example, living at roadside sites), this group are particularly vulnerable to having untreated long-term conditions, disrupted medical treatment, and barriers to accessing referrals, such as frequently changing addresses and lack of access to post, and limited literacy, which impacts on their ability to read follow-up letters or invitation to screening. Poor outcomes and morbidity are further exacerbated by a high rate of injuries on poor-quality roadside sites and poor diet and medication compliance (Cemlyn et al, 2009).

The CLG (2012) ministerial report on improving outcomes for Gypsies and Travellers emphasised barriers to accessing healthcare for these vulnerable groups and made a number of pledges to improve the health of all members of the populations, with a specific emphasis on the commissioning of specialist services. Specialist outreach diabetes care could potentially be provided by a multidisciplinary team of community health nurses engaging with "roadside Travellers". This already occurs in some localities where clinical commissioning groups or a consortia of practitioners co-fund Traveller health specialists.

Similarly “trusted” health professionals could assist in introducing diabetes specialists to Gypsies and Travellers on unauthorised sites or at temporary stopping places.

### Breaking down the barriers to care

This short article has emphasised a number of the key elements that underpin the high rate of diabetes amongst Gypsy and Traveller populations, as well as barriers that can stand in the way of people accessing health advice or an early diagnosis for diabetes.

Overall, as suggested in recommendations by Van Cleemput (2012) and Greenfields and Lowe (2013), the most effective way of delivering culturally appropriate preventive advice appears to be through a combination of community health advocates (trained members of the Gypsy and Traveller communities who work alongside healthcare professionals to deliver health promotion messages to their local population), and largely visual materials featuring images familiar to the target audience. There are a number of examples of culturally accessible health promotion materials that refer to healthy eating and symptoms of diabetes that have been produced by NGOs and agencies (see *Box 1*). There are also a number of locally produced booklets from local authorities and former health authorities (for example, Bristol and Cambridgeshire), which provide examples of traffic-light systems for food, recommendations for exercise and illustrations of “healthy plate” meals.

Specialist outreach health visitors or GP surgeries with interested and experienced staff can potentially offer longer appointments to Gypsy/Traveller community members. Importantly, Gypsy and Traveller respondents overwhelmingly report that when seeking medical care, they wish to be unhurried, treated with respect and dignity, and not

subjected to stereotypes or assumptions. For example, one Traveller explained:

*“I don't want to spend all my time talking about what it is like living on a site – I come to see the nurse to be treated, not to be interviewed like I am on reality TV.”*

Simple courtesies and an understanding of the challenges faced by Gypsies and Travellers are important. For example, the 2011 census indicated that more than 10% of Gypsies and Travellers were involved in delivering unpaid care to relatives and friends, often in excess of 50 hours a week, and research has shown that a substantially higher percentage of women from these communities undertake significant caring duties for elderly or disabled family members (Greenfields and Brindley, in press). Other challenges include literacy issues, which may prevent understanding of instructions or form-filling and the threat of eviction, or living on a site that is at risk of flooding, can cause problems in attending clinics, as can lack of IT access. Cultural preferences and professional expectations that an individual will follow a specific “diabetic” diet that may be difficult to prepare, unfamiliar or unpalatable may also increase communication barriers and avoidance of appointments. Knowledge of these challenges can make a substantial difference in developing trust between Gypsies and Travellers with diabetes and diabetes specialists.

Most importantly of all, taking time to get to know local community members and spending time with specialist staff who have already built up knowledge and relationships can be helpful. Experienced colleagues may also already be working in a cross-disciplinary manner to support access to care. Whilst the complexities of personal relationships and the building of trust can be a slow process and may be challenging at times for practitioners familiar in working in more rigid clinical settings, when working with Gypsies and Travellers, informality and opportunistic advice or diagnoses may be the only way to proceed in enhancing health.

It is beyond the scope of this article to consider the recent policy and practice changes that may go some way to ensuring more effective diabetes care for Gypsies and Travellers; however, it is worth noting that there is significant scope for

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#### Box 1. Health promotion materials aimed at Gypsy and Traveller communities.

- **Derbyshire Gypsy Liaison Group:** A diabetes specific leaflet can be found at <http://bit.ly/1ICcGYU>
- **Diabetes UK and Friends, Family and Travellers:** <http://bit.ly/1iMlOVr>
- **Irish Traveller Movement:** <http://bit.ly/1uuqY1T>
- **Bristol City Council Gypsy and Traveller Team:** <http://bit.ly/SdeHAH>

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encouraging surgeries to expand use of Read codes to include Gypsies and Travellers, which will permit better health surveillance and monitoring of the populations.

At present, as noted by the Irish Traveller Movement in Britain (2012), record keeping in relation to these populations is erratic and varies significantly, even within areas. Despite lobbying from NGOs and practitioners, at the moment the NHS Information Centre for Health and Social Care does not include Gypsies and Travellers as one of the 16+1 ethnic minority categories, despite their inclusion in the 2011 national census. Similarly, strategic practice and influential decision making varies significantly and typically omits consideration of Gypsy and Traveller health issues. However, this may occur at a clinical commissioning level, allowing staff with an interest in this population to suggest tailored interventions where there are known to be high numbers of Gypsies and Travellers. Salway et al (2013) stress that there is a real opportunity to improve outcomes for vulnerable minority ethnic groups through strategic commissioning processes whilst Gill et al (2013) have developed an evidence-based commissioning guide, which emphasises best practice in delivering services to Gypsies and Travellers and other hard-to-reach groups.

Nurse practitioners who are willing to think outside the box and take chances in suggesting positive change, as well as demonstrating leadership in identifying future initiatives, will be instrumental in bringing about real and lasting improvements in the health of these often marginalised communities.

Many Gypsies and Travellers, who have reluctantly experienced enforced change in their lifestyle, may look back on their lives and claim: “It was a sweet life travelling” – but now it is time to help them build a healthy one. ■

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