



**FRIENDS,
FAMILIES &
TRAVELLERS**

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Understanding Diabetes in Romany Gypsy, Traveller, and Roma communities

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Introduction	4
Acknowledgements	4
Background	5
Community background	5
Health background	6
Health data	6
Social Determinants Influencing Gypsy, Roma and Traveller Health	6
Discrimination	6
Education	7
Employment	7
Accommodation	7
Methods:	8
Literature review	8
Steering group	8
Focus groups	8
Interviews and conversations	9
Community members	9
Friends, Families and Travellers FFT	9
Healthcare professionals and allied healthcare professionals	9
Other charities	10
Academics	10
Industry	10
National guideline creators	10
Incorporation of work from previous and ongoing projects (digital exclusion)	10
Results:	10
Insights from the literature and existing resources search	10
Insights from the focus groups	11
Low health expectations	11
Low health literacy	11
Lack of knowledge about signs and symptoms	12
Challenges with management	12
Medications management	13

Diet.....	14
Challenging management and prevention of complications.	15
Impact on daily nomadic life	16
Impact on mental health.	16
Impact on finances.	17
Access to diabetes technologies.	18
Recommendations from the community:	18
Insights from academic research:	20
Insights from other charities:.....	21
Insights from healthcare professionals:	22
Outputs:	23
For community members	23
General knowledge about diabetes including diagnosis and complications ...	23
Information about accessing health care and supplies and medications	23
Nutritional information.....	23
Mental health.....	23
Financial	23
Complications awareness.....	23
Delivery and distribution of BreatkthroughT1 (Formerly JDRF)	23
Diabetes community champion	24
For healthcare professionals	24
Conferences:	24
Royal Society of Medicine : Health Inequalities in Digital Health 23/10/2024	24
Diabetes Professional Care 15/10/2024.....	25
One pager	26
NICE.....	Error! Bookmark not defined.
For the developers of medical devices.....	26
Resources provided by industry.....	26
When creating the devices	26
MHRA.....	27
Discussion.....	27

Health Expectations and Awareness of Diabetes	28
Health Literacy and Culturally Inappropriate Resources	28
Access to Healthcare and Diabetes Management	29
Barriers to Effective Diabetes Management	29
Mental Health and Emotional Impact	29
Financial Barriers	30
Recommendations for Future Actions	30
Annex.....	Error! Bookmark not defined.
Royal Society of Medicine – Health Inequalities in Digital Health 23/10/2024	
.....	Error! Bookmark not defined.
Annex.....	31
Focus group questions	31
Background and diagnosis:	31
Management and complications:	31
Impact on mental health:	31
Impact on daily life, specifically addressing roadside/nomadic lifestyle:	32
Financial challenges:	32
Tech support / digital access:	32
Recognising symptoms, prevention, and early diagnosis:	33
About us	33

Introduction

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Background

Community background

The term Gypsy, Roma and Traveller (GRT) encompasses various communities including Romany Gypsies (English Gypsies, Scottish Gypsy Travellers, Welsh Gypsies, and Romany people more widely), Irish Travellers, New Travellers, Liveaboard Boaters, Showmen and Roma. Each of these communities have rich and distinct cultures and histories. This diversity includes some groups, families or individuals being more traditional with cultural practices and way of life, with others being less traditional. It is therefore important to note that not all issues or health inequalities discussed may be relevant or applicable to all Gypsy, Roma and Traveller people. Furthermore, use of the 'GRT' grouping is not always preferred as it does not reflect this diversity; it is however often used in policy and research contexts.

There is a lack of accurate data to reflect the size of all communities under the Gypsy, Roma and Traveller umbrella. In the 2021 UK Census, 172,465 people from the Romany Gypsy, Roma and Irish Traveller communities disclosed ethnic status,

however, it is likely that the official census record is an underestimate of the true population size.

Health background

Health data

Due to chronic exclusion across mainstream health datasets, it can be difficult to obtain a clear picture of the health status for Gypsy, Roma and Traveller communities in the UK. However, the data we do have shows:

- Members of Gypsy, Roma, and Traveller communities have the [worst health outcomes of any ethnic group](#) in the UK (Committee, 2019).
- The [2021 census](#) for England Wales revealed that 14% of Gypsy or Irish Traveller respondents described their health as “bad” or “very bad”, which is more than twice as high as the White British group.
- The [Race Disparity Audit](#) revealed that Gypsy and Traveller people are less likely to be satisfied with access to a GP than white British people (60.7% compared to 73.8%) and are also less likely to be satisfied with the service they receive (75.6% compared to 86.2% for White British) (*Satisfaction with Access to GP Services - GOV.UK Ethnicity Facts and Figures*, n.d.).
- [42% of English Gypsies are affected by a long-term condition](#), compared to 18% of the general population (Gill et al., 2013).
- Roma communities experience specific social exclusion factors and barriers in access to health and care services. They have multiple overlapping risk factors for poor health and a [life expectancy up to 10 years less than non-Roma communities](#) in Europe (“Closing the Life Expectancy Gap of Roma in Europe - EPHA,” n.d.).

Social Determinants Influencing Gypsy, Roma and Traveller Health

Discrimination

Members of Gypsy, Roma and Traveller communities can experience high levels of discrimination throughout their lives, which has a direct impact on health and wellbeing. The 2018 Equalities and Human Rights Commission report [Developing a National Barometer of Prejudice and Discrimination in Britain](#), found that more people expressed openly negative feelings towards Gypsy, Roma and Traveller communities (44%) than any other group, double that towards Muslims (22%), and transgender people (16%), which were the next highest groups (Abrams et al., n.d.).

This figure is borne out in other surveys, showing high levels of prejudice and negativity held towards Gypsy, Roma and Traveller people.

Education

Gypsy, Roma and Traveller children have the lowest educational attainment at all key stages and have the highest rate of school exclusions out of any ethnic group in the UK. (*Education Inequalities Facing Gypsies, Roma and Travellers in England Friends, Families & Travellers, 2023; Permanent Exclusions - GOV.UK Ethnicity Facts and Figures, n.d.*)

Employment

Gypsy, Roma and Traveller individuals have a higher risk of poor health due to high levels of unemployment. According to the 2021 Census, 41% of Gypsies and Irish Travellers were employed or self-employed, compared to 70.9% of the wider England and Wales population, and 28.5% of employed Roma work in elementary occupations, while the national average is 10.5% (*Gypsy or Irish Traveller Populations, England and Wales - Office for National Statistics, n.d.*).

Accommodation

Inadequate housing and poor living conditions can directly impact health and wellbeing. 48% of Roma Support Group's health advocacy project service users stated they face mental health challenges relating to „poor housing conditions“ (*Roma-Mental-Health-Advocacy-Project-Evaluation-Report.Pdf - Google Drive, n.d.*). The lack of appropriate accommodation available for Gypsies and Travellers exacerbates inequalities in health and standards of living; a national shortage in both permanent and transit Traveller sites across England directly contributes to this. Furthermore, a lack of a fixed address can negatively impact health, as it can pose a barrier to accessing health services. Despite NHS guidelines indicating that a fixed address is not necessary for GP registration, many patients are wrongly refused on this basis (*Locked out: A Snapshot of Access to General Practice for Nomadic Communities during the COVID-19 Pandemic - Friends, Families and Travellers, n.d.*).

In the context of these health inequalities, we identified a need to look at access to diabetes technology and resources in the Gypsy, Roma and Traveller communities. The timing of this project coincided with the CORE20PLUS5 priority of diabetes in

[children](#), which helped with engagement of policy stakeholders (*NHS England » Core20PLUS5 Infographic – Children and Young People*, n.d.).

Methods

This project was co-created at every stage and morphed to fulfil the needs and requests of the communities.

Literature review

An initial literature review of available research and current resources for those living with diabetes led to an identification of those working in this space, along with a realisation that most of the current resources available were not appropriate culturally or from a literacy perspective which then informed the next stage our project.

Steering group

We set up a steering group consisting of FFT staff and community members. This steering group met monthly and informed the changes in strategy as the project progressed in response to the findings of our research.

Focus groups

- Three focus groups with community members in addition to informal conversations generated by these focus groups generated ongoing insights. To overcome health and literacy barriers including taboos, we facilitated Gypsy, Roma and Traveller advocates. They were both in person and online.
- Number of members in the group: 15
- A wide range of age, ethnicities, types of diabetes and roles were represented in these focus groups.
 - Conditions:
 - LADA
 - Type 2
 - Type 1 diabetes
 - Prediabetes
 - Gestational diabetes
 - Ethnicities:
 - Romany Gypsy
 - Irish Traveller
 - Roma

- Showmen
- Roles:
 - Community members living with Type 1 and Type 2 diabetes
 - Carers of people living with Type 1 and Type 2
 - Community members
 - Community leaders in other areas (Women's group and Driving group)

Interviews and conversations

Community members

In addition to the focus groups, we spoke to community members affected by diabetes in a variety of settings.

- *Drop-in centers in Cambridge and Cottenham:* community members were attending for wider help covering aspects such as housing and benefits. This proved to be an opportunity to speak and educate those who may not always prioritise their own health.
- *Attendees at the Cambridge fair:* Cambridge City Council are working in collaboration with The Showman's Guild to provide a variety of health and education support and advice services for the Travelling Communities at Cambridge Mid Summer's Fair. We attended the fair with a stand and spoke to community members as to what would be useful for them, therefore capturing people who are a target for preventative strategies.
- *Community members supporting those living with diabetes:* Valuable insights were gained from these carers who were sometimes better at seeing the challenges that those living with diabetes had normalized.
- *Caseworkers* supporting the Roma community.

Friends, Families and Travellers (FFT)

- This project led to the identification of community members living with Type 1 and Type 2 diabetes who came forward when we put a call out for people to take part in the steering group.
- Additionally, internal FFT case workers came forward to explain their own experiences helping community members and where they felt there were gaps.

Healthcare professionals and allied healthcare professionals

- GPs including those finding interim solutions to overcome the lack of data due to a deficient NHS data dictionary which, in England, does not provide an option to record Gypsy, Roma and Traveller ethnicity.

- Hospital pharmacist
- Endocrinologists
- Social worker

Other charities

- Jimmy's Homeless
- Good Things Foundation
- Breakthrough T1 (formerly JDRF) Type 1 diabetes charity

Academics

- Backgrounds in maternal health, public health, refugee health and social prescribing.

Industry

- Representatives at diabetes conferences including those in charge of website content and diabetes education.

National guideline creators

- Conversations with those in charge of looking at direction but also with the dissemination of national policies and guidelines.

Incorporation of work from previous and ongoing projects (digital exclusion)

- Overlap of insights into digital health inclusion especially as regards diabetes technology.

Results:

Insights from the literature and existing resources search.

The preliminary literature search and work highlighted areas lacking in appropriate content, which included:

- **Costs of Diabetes Management:** Lack of videos discussing the financial aspects of managing diabetes.
- **Nomadic Lifestyle Challenges:** No content addressing how nomadic lifestyles uniquely impact diabetes management.
- **Getting and Understanding a Diagnosis:** Limited information on the diagnostic process and understanding the results.
- **Sexual Health and Fertility:** Few videos on sexual health and little content on fertility issues related to diabetes.

These challenges with existing resources are relevant to other communities with low health expectations and literacy.

This literature review also showed how little work has been done on diabetes in Gypsy, Roma and Traveller groups, especially regarding Type 1 diabetes and access to medical technologies.

Insights from the focus groups

Low health expectations.

Across all Roma, Gypsy and Traveller groups, there was a clear tendency to low health expectations for themselves and their family members. With regards to diabetes, this manifested itself as seeing diabetes as an age-related and inevitable condition. “Taken with the sugar” was heard several times with a sense of fatality and for anyone who is over the age of 50, a diagnosis of diabetes is not a surprise but the norm.

It was also observed that other prioritize their family’s health over their own and a general reluctance to attend hospital appointments if a family member is ill.

“diabetes runs in my family, my grandad killed himself and my nan got shock diabetes, treated with milk and sugar – they stagger around and look like they’re drunk, easy mistake to make – cup of milk mixed in with sugar”

Low health literacy

In addition to not understanding that Type 2 diabetes is potentially reversible especially in the early stages, there was a lack of understanding as to how to manage it once a diagnosis was given. In part this was due to inappropriate information, either due to it not being in the right language (Roma), or in a written format and inaccessible if illiterate (Travellers and Gypsies), or culturally inappropriate (all). Participants faced challenges in understanding their diagnosis and its implications for their health. Resources are too text-heavy, not community-friendly.

- *“The leaflets aren’t suitable even if you can read.”*
- *“The dietary advice they give you doesn’t fit in with what our diets are.”*
- *“I wish they’d given more 1 to 1 advice”*

The consequences are best summed up by a community member, as *“it’s just not feasible advice, a lot of people switch off”*. Furthermore, there was no understanding of the difference between Type 1 and Type 2 diabetes.

Lack of knowledge about signs and symptoms

During the focus groups, there was a repeated request to improve community members' knowledge about signs and symptoms to avoid late diagnosis, which is very common. Due to lack of regular primary care contact, a diagnosis of type 2 diabetes was not generally through a regular screening program but rather when a complication appeared, such as a badly healing wound or a heart attack. Participants stress the importance of receiving personalised advice and support earlier in their diabetes journey.

"Symptoms most people would just put down to aging".

"I had no information about it. I just went for a blood test, and it came back Type 2".

"Diagnosed with Type 2 about 10 years ago, at the time I was 18 stone in weight. Went into the hospital for other issues, had a gastric sleeve for my weight. They gave me a lot of leaflets, but none of it is GRT community friendly".

Challenges with management

This leads to further worsening their health outcomes as even when an often late diagnosis was made, challenges with managing diabetes led to earlier and worse complications. These complications in turn impacting their ability to work due to their need to drive. There was a common feeling of not being supported and not being in follow-up programs to help with management.

Positive experiences involved doctors who listened and were committed to finding solutions. Negative experiences included difficulties in accessing knowledgeable doctors and having to advocate strongly for necessary tests and care.

Participants expressed the desire for someone knowledgeable about diabetes to provide reassurance and answer questions. Community members are often best placed to explain how these needs can be met and it was stressed that support does not necessarily need to come from a doctor but could be from a peer or a diabetes expert. A dedicated helpline for diabetes support could provide immediate assistance and reassurance, whilst a support group on WhatsApp could offer a platform for sharing experiences, asking questions, and receiving peer support. Participants

explained that they prefer practical support, such as guidance on medication management and diet, over passive information dissemination.

It was highlighted that short videos on social media platforms like TikTok can raise awareness among wider audiences and this influenced our project outcomes. Online forums were also mentioned, particularly platforms like Facebook, as potential providers of peer support and sharing of experiences, with moderation by healthcare professionals could improve the reliability and safety of information shared. These communities would ensure people are not lost in follow-up.

“Once I'd given birth no more diabetes follow up... I was told there was supposed to be follow up apps to make sure it didn't turn into type 2 – that was 2 years ago and I was just left “

Medications management

In communities with higher levels of digital, health and general literacy or language barriers, workarounds can be dangerous and optimization of chronic medication does not happen. Our focus groups revealed that the health care professionals were unaware of these issues with medicines management and were therefore unable to impact on them.

“They don't tell you the side effects of medication. If you can't read, you don't know. Nobody explains why you need to take them”

“I was given a glucose meter and told to get on with it, but I felt left to manage this on my own. I had to educate myself and find out what worked for me”

“When I fed back that I was dyslexic, they didn't give me an alternative, just said get on with it and you have a partner”

“Tried 4 different medications but doesn't work because of other underlying conditions. Diabetes still not under control A year and a half later, I still got all the symptoms and still no management”

“Side effects - ‘you're meant to read that yourself aren't you? But if you can't read...”

We heard about people using the colour of the medication boxes to guide them as to which insulin or medication should be used and at which time. This places them at a risk of acute and chronic life-threatening events.

Due to hesitancy about engagement with primary care and unawareness of the need to review medications, community members were unaware that their insulin dose may need to be changed over time.

Diet

Type 2 diabetes is influenced by diet, both in cause and then in causation of complications. Although there is great variability in the type of diet between Gypsy, Roma and Traveller communities, there is a common lack of understanding how much diet can impact diabetes and how to resolve these issues.

"I would say that the nutritional advice given by the hospital is absolutely horrific. They don't teach you what you can safely eat without spiking blood sugar levels (I was told it's ok to have toast for breakfast for example) - I actually learned most of the important stuff from a website called Gestationaldiabetes.co.uk"

"Doctor just gave me my medication, there wasn't enough support. Dietician didn't link up with diagnosis. You have to seek out information yourself."

"Increase awareness in everyday settings like petrol stations by displaying pictures of healthy snack options"

Some of the community specific challenges include the fact that dietary advice doesn't match what the community eats. Furthermore, Gypsy and Traveller families may assume that large meals are necessary, whereas smaller portions could suffice. Red Bull is often used by community members to obtain energy for long days of work or childcare, with no understanding of the sugar content. A previous FFT project successfully swapped out energy drinks for reusable water bottles with individuals' names on them. The Roma diet can contain a lot of fat and sugar and at the same time traditional diets have changed to more processed foods.

Some people mentioned that on diagnosis they were going to extremes of change in types of food eaten, with no real medical or official dietician input. Managing different dietary needs with couples added another layer of complexity. Much more common was that people were aware on a high level that their diet impacts their diabetes, but did not have the specific knowledge to change their diets, so didn't. Dietary advice often focused on what foods to avoid, such as bread, rather than balanced moderation and illiteracy meant issues reading and identifying suitable food packages.

Suggestions for a specific diabetes cookbook for Irish Travellers which crossover into other communities included:

- Recipes should use ingredients that are easy to find, even in remote locations.
- Preferably recipes that require minimal or simple ingredients.
- Convenient one-pot meals.
- Emphasis on incorporating fresh fruits and vegetables, such as berries.
- Recipes should cater to varying cooking conditions, including potentially unreliable fridge temperatures.
- Portion sizes should be carefully considered for diabetes management.
- Preference for fresh herbs over stock cubes for flavouring
- Carb counting for Joey Grey (traditional gypsy stew) so that when it was eaten, insulin could be dosed accordingly.
- A barcode system that links to cooking tutorials for convenience.
- Family friendly.
- Visual aids and clear measurements are helpful, especially for those who prefer a more traditional cooking style.

There was no insight into the relationship between exercise and blood sugar control.

Challenging management and prevention of complications.

Participants had to chase for foot check appointments and only knew about the importance due to family experience. Some had been on a waiting list for over a year without follow-up, with providers citing long waiting lists as the reason.

There was a lack of awareness about lifelong effects and mortality risk.

“you say Type 2 – that’s okay not as serious, - learned it actually was bad didn’t realise how serious it was “

“wherever [showmen] ... are they have to have electric to manage – so they’ve had to settle now, leave the life – if it was given earlier it wouldn’t get to the stages ...the dietary advice is just diabolical”

“My cousin lost both his legs and died not long after. People from the community don’t know much about it.”

“43 year old man on our site had a late diagnosis, he lost his vision. Now he’s had the support but it’s too late”

“Never told me about consequences, could be deadly, could lose limbs or eyesight never told about side effects of medication”

Impact on daily nomadic life

Most people do live in bricks and mortar housing now - some not by choice but in order to manage their diabetes better, but at the cost of their mental health due to being isolated from their family and community and traditional way of life.

Intermittent electricity leads to issues with maintaining the insulin cold chain and fresh ingredients in good condition. This also impacts on the ability to charge medical devices. Emergency power and batteries should be available on private sites.

Being nomadic also leads to issues with accessing medications and this too impacted on our choice of resources to create for the community. Storing medications, especially insulin that requires refrigeration, was a significant challenge for participants living a transient lifestyle, which led to high levels of stress.

Participants express a need for roadside hubs where they can access necessary amenities, including facilities for storing medication. Access to power sources for charging devices is crucial, but not always readily available, especially for older vehicles. Accessing medical care in the first place was a challenge due to challenges with wifi and internet connections to get online. As regards diet, there is difficulty in maintaining proper nutrition while on the road due to lack of information and resources. Petrol stations often not stocking appropriate healthy options at an affordable price.

"In terms of management while on the road, you are relying on electricity, which is not always possible. My cousin is a showman, and he had to come off the road and give his children a different life because of the lack of information and support available while travelling."

Impact on mental health.

Participants did not feel confident in managing their diabetes, highlighting the need for support and education. There was a sense of isolation due to lack of support; participants expressed that there is often nobody to turn to for help. Managing diabetes feels like a full-time job, leading in turn to burnout, especially in those using insulin.

'My diabetes is not being managed how it should be managed. I find it really hard to get any information out of anyone, and it frightens me'

"its a job in itself! And if its gestational you've often got lots of little ones running around"

“Didn’t know anything about it, then told it was life threatening. Can be very intense”

Men specifically were cited as needing more empowerment and motivation to take ownership of their diabetes management. Family struggles were shared, including blindness and the inability to drive, affecting family dynamics and independence. Assumptions and stigma around diet and weight leading to diabetes caused emotional distress and participants felt judged and stigmatised, with people assuming their diabetes was solely due to poor diet and weight.

The risk of hypoglycaemia can lead to isolation, as participants feel unsafe leaving the house alone, leading to increased feelings of loneliness and isolation. Generally difficulty stabilising blood sugar levels with metformin or insulin are leading to significant physical limitations and safety risks, particularly during physical exertion.

“Didn’t know anything about it, then told it was life threatening. Can be very intense”

“I don’t think my diabetes has been managed how it should be – i feel scared and apprehensive in terms of what my future holds. I’ve had nothing explained to me, it’s scary. I’m not a wallflower, I speak out and I can read and write – but it’s still been so hard to get information out of anyone.”

“I feel that diabetes is currently ruining my life and if i joined [the online focus group] I’d spend the whole time crying.

Impact on finances.

Financial implications made maintaining a healthy diet difficult. Food banks and hubs were often not suitable due to high-carb food options and lack of gluten and dairy-free alternatives, creating additional stress for participants.

“Trying to find foods in the price range was really hard – especially with everything else going on – you end up just skipping a meal! It’s a lot of money to go for the healthier options.”

*“Even in hospital, on the ward, they couldn’t accommodate it at all – had to go downstairs to the shop and spend more money! You’d think they’d accommodate to that but I don’t think they have a clue really for women with diabetes, even in a healthcare setting
school dinners and hospital food are the worst – which is terrible! “*

Missing school time and appointments incur invisible costs, both financially and academically. Participants were unaware of the benefits they could opt into.

Access to diabetes technologies.

Most of the participants were not using technologies such as pumps or sensors. Not through lack of interest or motivation but because it wasn't offered. For many of the participants, it was the first time they learnt about CGMS and insulin pumps.

"It would be helpful to have the sensors on your arms instead of having to prick your finger. It is a lot more convenient, especially when having busy family lives and children to take care of"

'If i had my away every diabetic would have access to technology – it is life changing"

Recommendations from the community:

The steering groups and focus groups were also used to inform what our outputs should be for community members, healthcare professionals and other stakeholders in the diabetes care journey. These included:

Education

- Use videos and community voices to spread awareness about diabetes symptoms and prevention. A series of short videos would be best – viewable on a phone and social media friendly especially for TikTok, YouTube and Twitter. Links should be through QR codes.
- Ensure people are aware of the symptoms of diabetes through campaigns and education efforts.
- Collaborate with organisations like FFT to disseminate information and raise awareness about diabetes.
- In-person peer support sessions like a clinic would be acceptable and effective. A community champion should be an 'ethnic community member' and could be trained up to do peer to peer support and education.
- As to whether resources should be community specific there were mixed responses due to potentially negative feelings of being 'targeted'. Keep open and clear, but relevant information and formats are key. When resources were tested on community members, community specific and relevant images were very positively received.

Diet

The focus group discussed the importance of offering alternative diet options, such as those provided by programs like Slimming World, which have been shown to work well for diabetes management. Participants suggested raising awareness that modern diets have evolved from traditional GRT diets, like Joey Grey, and emphasized the need to focus on more contemporary, evidence-based dietary choices. It was recommended that local artists be engaged to create visual representations of healthy recipes and meal plans, making the information more accessible and appealing to the community. The group also highlighted the importance of encouraging healthier food choices and educating individuals about the dangers of high salt and sugar content in traditional GRT diets.

Additionally, the group suggested offering a selection of standard food choices that cater to various dietary needs and preferences, ensuring inclusivity for all community members. To further promote healthier eating habits, it was proposed to host food demonstrations at FFT, showcasing practical cooking techniques and providing opportunities for hands-on learning. A key recommendation was the creation of a recipe book, not just with traditional recipes but also with principles for meal planning and portion management. This resource should emphasize using affordable ingredients and feature visual instructions for measurements, such as cups and tablespoons, to reduce the reliance on scales or specialized equipment. The format of this resource could be shifted from a book to video tutorials, providing a more accessible and engaging format for the community. Education on core principles of healthy eating, rather than rigid rules, would also empower individuals to make better choices, particularly when needing quick, on-the-go options that fit into their busy lives.

Addressing financial challenges

The focus group discussed the importance of providing information on available financial support options, such as Disability Living Allowance (DLA) or Personal Independence Payment (PIP), to individuals managing chronic conditions like diabetes. Participants highlighted the significant financial implications of diabetes management, noting that it not only incurs direct costs for healthcare, medications, and supplies but also creates indirect financial burdens. These include missed work opportunities and increased childcare needs. Additionally, the group emphasized the value of offering training around diabetes management in food banks to raise

awareness and equip those in need with the necessary tools and knowledge to manage their condition effectively.

Insights from academic research

Challenges and Solutions:

One of the key challenges identified was the lack of knowledge surrounding diabetes complications and screening, particularly when it came to culturally sensitive issues. Several groups were found to exhibit symptoms of diabetes, yet they had no prior screening or awareness of the need for it. To address this gap, onsite health checks were conducted within established community groups, focusing on critical aspects such as foot care and diabetes screening. The approach also emphasized the importance of culturally appropriate education, with a focus on translating NHS knowledge into accessible formats for diverse populations.

Health Education and Awareness:

The need for increased awareness around the high sugar intake, particularly from energy drinks, was another major topic discussed. Myths about hidden sugars were addressed, with a focus on dispelling misconceptions. Additional concerns included post-bariatric surgery care and travel-related healthcare challenges. A lack of awareness about NHS services and the free access to healthcare was also noted as a barrier to proper diabetes management within the community.

Community Engagement:

Community engagement relied heavily on informal chats and word-of-mouth to disseminate information. There were significant challenges in accessing opticians and maintaining prescriptions while traveling, which highlighted gaps in healthcare accessibility. Church missions were used as a platform for health information dissemination, despite facing cultural mismatches. Moreover, there was an identified need for menopause support and cultural adaptations in diabetes management.

Outcomes and Reflections:

Despite these challenges, Community Health Workers expressed pride in facilitating conversations and addressing previously unmet needs within the community. Personal experiences of exclusion among the workers helped shape their approach,

fostering a deeper sense of empathy and understanding towards the individuals they served.

Insights from other charities:

Lessons learned from organizations such as the Jimmy's Homeless charity emphasize the importance of cascading learnings and messages from peers within marginalized communities, particularly when addressing health issues in Gypsy, Roma, and Traveller (GRT) populations. It is crucial to make health messaging relevant to current conditions, shifting the focus from merely ruling out illnesses to proactively promoting health checks. This positive, forward-thinking approach encourages individuals to check their health status rather than avoiding it due to fear or lack of awareness. Diet-related issues, such as the high intake of sugar due to limited diet options and donations often being sugary, further exacerbate health concerns within these communities. The charity also highlighted that people within marginalized groups often have low health expectations, with many not looking beyond a short-term outlook (e.g., two weeks), which affects their engagement in long-term health management. Additionally, symptoms of diabetes are often misattributed to substance use, further delaying diagnosis and treatment.

Furthermore, Breakthrough T1d (formerly JDRF) suggested integrating tech discovery days at community events such as football stadiums, offering an innovative way to engage the public and raise awareness about diabetes and its management. The potential for collaboration with health trusts for major community events, like the Appleby Fair, is also an opportunity to broaden the reach and inclusivity of diabetes-related education. Including various professionals—such as psychologists, educators, medtech experts, and podiatrists—during these events can ensure that a holistic view of diabetes care is presented. Additionally, continuing accessibility projects, such as those led by Chris Bright, remains essential for improving community engagement and addressing specific health needs in underserved populations.

Insights from healthcare professionals:

A dedicated, consistent team approach, as seen in type 1 diabetes care, tends to foster good engagement, with community members showing a willingness to trust and follow care pathways. This model presents an opportunity to secure funding for secondary care pathways that ensure continuity of care and help prevent unnecessary emergency department visits. However, several issues have been identified, particularly with parents of children with type 1 diabetes, such as confusion about where Continuous Glucose Monitors (CGMs) are delivered, with deliveries to pharmacies often being more accessible than to private addresses. Additionally, there is a general misunderstanding regarding the seriousness of diabetes, which can lead to delays in proper treatment and care. Medication reviews are often inconsistent, with many patients receiving the same medications for extended periods without a proper review or adjustment. There are also challenges with receiving the necessary devices, such as insulin pumps and receivers that do not require mobile phones, as well as logistical difficulties in obtaining supplies depending on the patient's postcode.

Further issues include challenges related to travel, with patients needing to purchase their own travel cool bags, and discrepancies in where and how sharps are collected. Local authorities often fail to provide adequate roadside sharps collection, and pharmacies are unwilling to take sharps back. To address this, a review of local pharmacies that accept sharps should be conducted. Another point of concern is the process when patients change GP practices. If a patient has been absent for more than three months, they may be deregistered, which can complicate continuity of care. It is also important to ensure that information such as a free Wi-Fi map for health professionals and the community is included in FAQs, with attention given to the time required to upload and make sure that the information leaflet remains accessible long enough for users to process the content. The integration of remote appointments also appears to be beneficial for continuity of care, particularly in areas where access to in-person services may be limited.

Outputs:

For community members

General knowledge about diabetes including diagnosis and complications

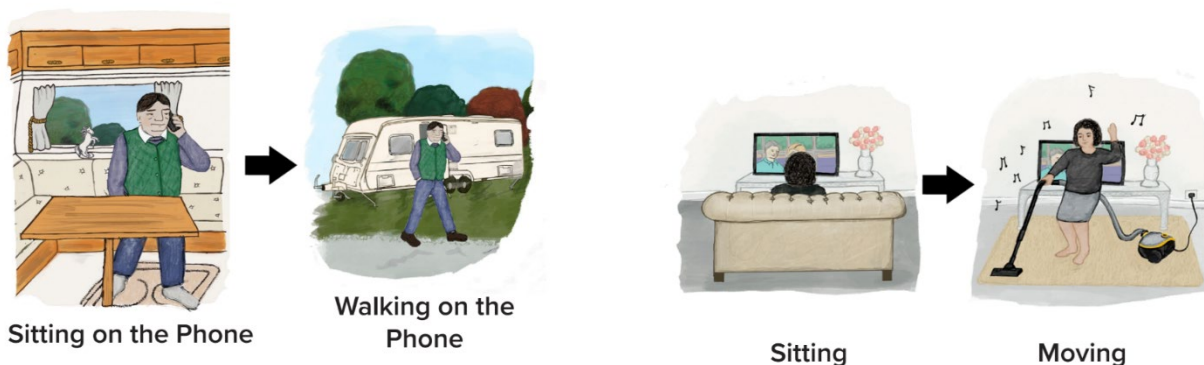
Community-relevant information was created through a focus group.

Information about accessing health care and supplies and medications

A short social media friendly guide to changing your designated pharmacy on the NHS app was created to complement the existing video about using the NHS app.

Nutritional information

For this project, the recipe books became swap cards. Full set of images available on request.



Mental health

A community member with extensive type 1 and type 2 experience was trained up to become a community diabetes ambassador.

Financial

Review of DLA and PIP forms with extra information for outreach teams helping community members fill in DLA and PIP

Complications awareness

Support to access relevant resources is through the community diabetes ambassador.

Delivery and distribution of BreakthroughT1 (Formerly JDRF)

We received 10 packs with Rufus the Bear and also resources for adults living with Type 1 diabetes. The adult versions were not culturally appropriate due to literacy issues but Rufus was a great hit in person and online in community Facebook and

WhatsApp groups, helping to engage the community with the project and the resources created.



Diabetes community champion

For healthcare professionals

Conferences:

Royal Society of Medicine: Health Inequalities in Digital Health 23/10/2024



The event, organised by Dr. Alice Byram as a member of the Digital Health Council, aimed to showcase important work and raise awareness of the challenges faced by Gypsy, Roma, and Traveller (GRT) communities in accessing diabetes digital technologies. The keynote address by Partha Kar focused on health inequalities in diabetes, providing a foundational understanding of the topic. Michelle Gavin, Head of Development, alongside Emma Bray, a community member and Diabetes

Ambassador, delivered a presentation that specifically addressed the challenges and potential solutions for improving access to digital health technologies for GRT communities. The discussion prompted conversations among panelists about the challenges in identifying populations with health inequalities, particularly due to the inability to codify GRT communities in the NHS England Data Dictionary.

Audience members actively engaged in the conversation both during and after the presentation, with many expressing increased awareness of the unique needs of GRT communities and what actions they could take to address them. These discussions have led to further dialogues on advancing efforts to update the NHS England Data Dictionary by incorporating the 2021 census categories, allowing for the identification of Gypsy, Roma, and Traveller populations. This update would facilitate the development of targeted health interventions beyond diabetes. As part of the ongoing efforts, a one-pager will be produced, including a list of pharmacies that will accept sharps for disposal and a map highlighting locations with free Wi-Fi for healthcare professionals and the community.

Diabetes Professional Care 15/10/2024

At the Diabetes Professional Care event held on October 15-16, 2024, at Olympia London, Emma Bray, a community member and Diabetes Ambassador, alongside Michelle Gavin, Head of Development, presented their findings on improving access to diabetes digital technologies within Gypsy, Roma, and Traveller communities. Their presentation addressed the unique challenges faced by these communities in accessing diabetes technologies and resources and proposed culturally tailored solutions to bridge the gap.

Caroline Blythe, Programme Manager within the Strategy Team of NHS England's National Diabetes Programme, provided positive feedback on the event. She commended the insightful presentations and discussions, highlighting their importance in raising awareness about health inequalities and the need for inclusive digital health interventions. This feedback underscores the event's success in fostering collaboration and driving forward initiatives aimed at reducing health disparities among underserved populations.

One pager

A one-pager for healthcare professionals, outlining key insights and recommendations from the Diabetes Professional Care event, was disseminated to several key organisations, including professional societies, NICE, and the Getting it Right First Time (GIRFT) programme. Dr. Fulya Mehta, NHS England's National Clinical Lead for Diabetes in Children and Young People, and Partha Kar were also included in the distribution. The one-pager aimed to raise awareness of the challenges faced by underserved communities, particularly Gypsy, Roma, and Traveller (GRT) populations, in accessing diabetes care and digital health technologies. By sharing this information with relevant stakeholders, the goal is to foster collaboration and drive policy changes to improve diabetes care and reduce health inequalities.

For the developers of medical devices

Resources provided by industry

FFT aims to offer cultural training to industry providers of diabetes technology, recognizing the importance of developing solutions that are not only technologically accessible but also culturally sensitive. It is essential to understand that low literacy does not imply an inability to navigate technology. Many individuals with lower literacy levels possess remarkable memories and adaptive skills that enable them to engage with tech effectively. To support this, tools like Text Reach, which provides text-to-speech and other accessibility features, can be invaluable in making resources more accessible. By offering cultural training, FFT hopes to equip industry providers with the knowledge needed to create diabetes technology solutions that are both inclusive and relevant to a wide range of user populations.

When creating the devices

When designing health technologies for diverse populations, several factors must be considered to ensure accessibility and effectiveness. One major consideration is device power, as many individuals in underserved communities have intermittent access to electricity. Devices should be designed to function with standard or rechargeable batteries, and options such as solar-powered devices could enhance sustainability and accessibility. Additionally, limited or no data plans may hinder the ability to upload and share health data, so ensuring devices support asynchronous data upload and offline functionality is essential. Furthermore, not all users have

high-end smartphones, which means apps must be optimized to use minimal storage and processing power to accommodate a wider range of devices.

Health literacy and cultural sensitivity are also crucial. Co-creating solutions with diverse users is key to meeting varied needs and expectations. Tools such as ReachDeck or similar platforms can support users with lower literacy levels. It is also important to consider privacy and sensitivity, allowing users to lock or hide sensitive data, such as information related to cancer or reproductive health. For populations with multiple comorbidities, continuity of care can often be lacking, so health technologies must ensure that data can be easily exported and shared with healthcare professionals. Lastly, representation and inclusion in data systems are vital. Outdated ethnicity categories should be avoided, and ethnicity options should be expanded and co-designed with the intended users to ensure more accurate representation and inclusion.

MHRA

The Medicines and Healthcare products Regulatory Agency (MHRA) has recently undertaken a consultation to update the regulatory framework governing medical devices in the United Kingdom, with particular attention to diabetes technology. This consultation, which concluded on January 5, 2025, sought input from a broad spectrum of stakeholders—including patients, manufacturers, healthcare professionals, and the general public—on several key areas. Insights from this project were submitted to this consultation.

Discussion

The findings from this project provide valuable insights into the health expectations and challenges faced by the Gypsies, Roma, and Travellers communities, particularly regarding diabetes management. These communities experience some of the most severe health disparities in the UK, with members facing unique barriers in accessing healthcare, understanding their diagnoses, and managing long-term conditions like diabetes. This section discusses key themes that emerged from the research and highlights both the limitations and potential pathways forward in addressing the healthcare needs of these communities.

Health Expectations and Awareness of Diabetes

One of the most significant findings from this project is the low health expectations that prevail within the Gypsies, Roma, and Travellers communities. Health literacy, particularly related to diabetes, is extremely low, and there is a general perception that diabetes is a condition that comes with age, family history, and inevitability. This belief contributes to a fatalistic view of diabetes, where it is seen as a part of life rather than a manageable or preventable condition. In focus groups, many participants expressed a sense of resignation, with diabetes being referred to as something "you get with age" and considered almost normal for older individuals. This view often leads to a lack of urgency in seeking care or managing the condition once diagnosed.

Additionally, there was a lack of understanding between type 1 and type 2 diabetes, with both being treated similarly in terms of health expectations. This confusion, combined with ill-suited resources that are culturally inappropriate or inaccessible due to literacy barriers, contributes to difficulties in managing the condition.

Health Literacy and Culturally Inappropriate Resources

The low health literacy levels observed across Gypsy, Roma, and Traveller communities are compounded by the fact that existing resources are largely unsuitable. This includes information that is text-heavy, culturally misaligned, or simply unavailable in languages and formats that are accessible to the community. Many participants noted that leaflets and educational materials provided by healthcare professionals were not only difficult to understand but also irrelevant to their daily lives. For example, dietary advice from hospitals often clashed with traditional Gypsies, Roma, and Travellers' diets, which are rich in sugar and fats and not easily adaptable to generalised, one-size-fits-all recommendations.

The literacy challenge extends beyond reading and writing, impacting digital literacy as well. With the increasing reliance on online resources and health apps, Gypsy, Roma, and Traveller community members face an additional barrier in accessing vital health information. This digital divide prevents them from engaging with resources that could offer practical advice on managing diabetes, further deepening the health inequalities faced by this community.

Access to Healthcare and Diabetes Management

Accessing healthcare is another major barrier for the Gypsies, Roma, and Travellers communities. Despite official NHS guidelines stating that a fixed address is not necessary for GP registration, many Gypsies, Roma, and Travellers individuals face difficulties registering with healthcare providers, primarily due to their nomadic lifestyles. The absence of a stable address prevents many from receiving continuous care or following up on diabetes management, which is crucial for long-term health.

The lack of consistent healthcare is compounded by the inadequate knowledge and support from healthcare professionals. Participants reported feeling neglected, particularly in terms of follow-up care. Many individuals were given glucose meters or medications without sufficient guidance on how to use them or manage their condition effectively. Moreover, participants shared stories of feeling abandoned by healthcare providers after being diagnosed, with no ongoing support or education on how to prevent complications.

Barriers to Effective Diabetes Management

The challenges in managing diabetes were also a key point raised by participants. Common obstacles include medication management, dietary restrictions, and the lack of consistent follow-up care. Many individuals relied on trial-and-error methods to manage their insulin and medication dosages, often without clear guidance from healthcare professionals. Furthermore, the high cost of medications and the lack of access to diabetic-friendly foods present additional hurdles. The issue of food insecurity was highlighted, with food banks often providing high-carb options that are not suitable for individuals with diabetes, exacerbating the financial strain on families.

Another significant challenge in diabetes management is the nomadic lifestyle, which brings additional complications in terms of medication storage (especially insulin), access to healthcare providers, and finding reliable electricity sources for monitoring devices. The need for practical, community-driven solutions, such as roadside hubs for accessing healthcare and medication, was repeatedly emphasized in the focus groups.

Mental Health and Emotional Impact

The mental health impact of living with diabetes, particularly in the Gypsy, Roma, and Traveller communities, was a theme that emerged strongly. The stress of

managing a chronic illness in a community where healthcare support is inconsistent can lead to feelings of isolation, burnout, and anxiety. Participants reported a lack of emotional support, as well as difficulty in discussing their diabetes with family and friends. The emotional toll of managing diabetes was often exacerbated by the stigma associated with the condition, which is frequently seen as a consequence of poor diet or lifestyle choices. This stigma, along with a general lack of understanding about the seriousness of diabetes, contributes to feelings of shame and a reluctance to seek help.

Financial Barriers

The financial barriers to managing diabetes were also significant. Many community members face financial difficulties, making it challenging to afford medications, healthy food, and the necessary tools for diabetes management. The lack of access to affordable healthcare further limits the ability to manage diabetes effectively, resulting in worsening health outcomes. This situation is made worse by the financial costs of missing school or work due to diabetes-related complications.

Recommendations for Future Actions

The findings from this project suggest several key recommendations for improving the health outcomes of Gypsies, Roma, and Travellers communities. First, there is a critical need for culturally appropriate, accessible resources that consider both health and general literacy levels. Health information should be presented in formats that are relevant and easily understood by community members, including visual aids, videos, and community-driven content such as social media campaigns. These resources should focus not only on diabetes but also on preventative measures and early detection of symptoms.

Second, there is a need for greater integration of healthcare services with the realities of the Gypsies, Roma, and Travellers lifestyle. This includes providing more flexible care options, such as the ability to register with multiple healthcare providers, and ensuring that diabetes management tools, such as insulin pumps and glucose monitors, are accessible and affordable. Community-driven solutions, such as mobile health clinics or roadside hubs, could help bridge the gap in care for nomadic individuals.

Finally, addressing the mental health impact of diabetes is essential. The creation of peer support groups, as well as online and in-person community support systems, could help reduce feelings of isolation and stigma. Empowering community members to take control of their diabetes management, through education and emotional support, is crucial for improving both health outcomes and quality of life.

In conclusion, while Gypsy, Roma, and Traveller communities face significant barriers to effective diabetes management, there are actionable solutions that can improve their health outcomes. By developing culturally relevant resources, providing more accessible healthcare, and addressing the emotional and financial challenges associated with diabetes, we can create a more supportive environment for these communities. The co-creation of health solutions with Gypsy, Roma, and Traveller community members will be key in ensuring that these interventions are both effective and sustainable.

Annex

Focus group questions

Background and diagnosis:

- What type of diabetes do you or your family members have, and how was it diagnosed?
- Did you encounter any challenges during the diagnosis process? What could have made it easier?
- Do you feel you understand what the diagnosis means and its implications for your health?

Management and complications:

- What yearly check-ups do you currently receive for your diabetes management?
- What yearly check-ups do you expect to receive?
- Have you experienced any issues accessing these check-ups? If so, what are the main challenges?
- How well do you understand the complications associated with diabetes?
- What concerns do you have about potential diabetes complications?
- How has your understanding of the signs and symptoms of diabetes affected your health management or that of someone you know?

Impact on mental health:

- How does living with diabetes affect your mental health and well-being?

- What support systems or resources would help improve mental health for those managing diabetes?
- How confident do you feel about managing your diabetes on a day-to-day basis?
- How comfortable do you feel talking about having diabetes with others?
- Are you able to inject insulin in public without feeling self-conscious? If not, what are the challenges you face?
- How open are you in sharing your diabetes diagnosis with friends or family?
- To what extent can you discuss the lifestyle changes required by diabetes with those around you? (e.g, dietary modifications, exercise routines, and medication management, stress management)
- What type of resources do you think would help your family and friends better support you in managing your diabetes?

Impact on daily life, specifically addressing roadside/nomadic lifestyle:

- What are the unique challenges you encounter in your daily life due to the roadside or nomadic lifestyle, and how do these challenges affect you managing your diabetes?
- What challenges do you face in accessing medical care and managing diabetes?
- How can healthcare services be adapted to better support your lifestyle?
- Do you involve your family and friends in supporting your daily diabetes management routine?

Financial challenges:

- What financial barriers or challenges do you and your family face when accessing diabetes care, medications, and supplies? I.e. is it difficult to eat the correct diet due to the cost of food increasing
- If you have accessed Food banks what issues have you faced?
- How does managing diabetes impact your ability to work, and do you face any indirect financial challenges such as time off work?

Tech support / digital access:

- What types of technology are you aware of that can help manage diabetes?
- How did you first find out about these technologies?
- Do you feel you have enough information about the available technology options for diabetes management? If not, what additional information would be helpful?
- What features or aspects of the technology have been particularly helpful for you?
- What factors do you think contribute to this resistance or pushback (e.g., cost, lack of knowledge, cultural beliefs)?
- Are there any barriers or challenges in accessing tech support or digital health tools for diabetes care?
- Can you provide examples of good practices or positive experiences you've had with diabetes management technology?
- How do you ensure that your diabetes devices stay charged?

- What online platforms do you use for advice and support? i.e. NHS Website, NHS apps, diabetes forums, google search
- Have you used any of the diabetes devices pumps etc. if so, what was your experience.

Recognising symptoms, prevention, and early diagnosis:

- What are the signs and symptoms of Type 1 or type 2 diabetes that you are aware of?
- How did you learn about the signs and symptoms of Type 1 or type 2 diabetes?
- Have you or someone you know experienced these symptoms? If so, can you share more about that experience?
- What do you know about the risk factors for developing Type 1 or type 2 diabetes?
- How did you come to understand these risk factors?
- Are there any misconceptions or uncertainties you have about the risk factors for Type 1 or type 2 diabetes?
- What educational resources or programs would be most effective in raising awareness about symptoms and prevention?
- Where do you typically get information about health issues like diabetes?

About us

Friends, Families and Travellers (FFT) is a leading national charity that seeks to end racism and discrimination against Gypsies, Travellers and Roma communities and to protect the right to pursue a nomadic way of life. www.gypsy-traveller.org

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